The Influence of Eating Habits and Nutritional Status on Overweight and Obesity in Children with Cerebral Palsy

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Introduction

PROBLEM STATEMENT

Obesity is an emerging problem for children and youth with special health care needs (CYSHCN). CYSHCN are characterized by the presence of a chronic physical, behavioral, developmental, or emotional condition that requires services that are different from other children (i.e. physician specialists; physical, speech, and/or occupational therapies; special education; family counseling, etc.).[1] CYSHCN require health and related services beyond the scope required by children without special health care needs. They are also at an increased risk of chronic physical, developmental, emotional, or behavioral conditions.[1] According to the CDC, CYSHCN have an obesity rate of 22% compared to 16% for children without disability.[2]

Cerebral palsy (CP) is the most common cause of physical disability in children. One in 323 children in the United States have been identified with CP.[3] Although prevalence data is limited, prevalence of obesity in children with CP has risen from 7.7% to 16.5% in one decade (1994-2004). This increase is similar to the increase in obesity found among the general population.[4]

Eating habits is a broad term that refers to what foods and when individuals eat; how they select, gather, and eat these foods; why they eat these foods and who they eat these foods with.[5] Healthy eating habits and physical activity are important factors in preventing obesity and overweight in all individuals and many studies have subsequently

addressed these risk factors. However further research to investigate risk factors specifically among children with CP is vital as additional chronic disease (i.e.- cardiovascular disease, type II diabetes) may complicate the child's existing condition and quality of life.[6]

IMPORTANCE OF STUDY

The National Institutes of Health (NIH) describes 'cerebral palsy' as "any one of a number of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination…" [7] CP is characterized by a range of non-progressive syndromes that affect posture and motor impairment.[8] These impairments are a result of damage to the central nervous system, which can occur in utero, during delivery, or during the first 2 years of clinical life. Signs of CP include spasticity, movement disorders, muscle weakness, ataxia, and rigidity.[9] The main characteristics of CP are motor impairments, neurologic issues, cognitive impairments, seizure disorders, or vision, hearing, or speech impairments.[9]

Risk factors of CP include preterm birth (<37 weeks of gestation), low birth weight (<2,500 grams), maternal infection, and disruption of blood and oxygen to the developing brain.[9,10] Life expectancy for children with CP has increased significantly over the past 50 years. Provided children with CP have adequate access to health care and do not suffer from serious comorbidities, their lifespan is expected to approach that of the general population.[9,10]

Types of Cerebral Palsy

The four main types of CP include: spastic, dyskinetic, ataxic, and mixed CP. These categories of CP are classified according to muscle stiffness, difficulty in

controlling movement, or difficulty with balance and coordination. Spastic CP, which refers to muscle stiffness or difficulty in movement, is the most common type of CP, accounting for about 80% patients.[11]

In addition to motor impairments, CP can also cause cognitive, visual, feeding and speech problems, along with epilepsy, gastrointestinal, and growth impairments. These impairments can severely affect quality of life in children with CP.[11] [See Appendix 1]

Causes of Cerebral Palsy

Although in many instances, the cause may be unknown, CP can be caused by congenital or acquired factors. Congenital CP suggests damage or abnormal development of the brain occurred before or during birth. Congenital CP accounts for the majority (85%-90%) of CP cases[12] Acquired CP refers to CP cases that are caused by brain damage that occurred greater than 28 days after birth. A primary cause of acquired CP includes infection or injury to the brain. Although in some circumstances little can be done to prevent CP, precautions such as treating infections, getting vaccinated, and preventing injuries can be taken before, during, and after pregnancy in order to reduce the risk of developing CP.[12]

Prevalence of Cerebral Palsy

Prevalence Rates of Children with Cerebral Palsy within the United States

Estimates from the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, have found that 1 in 323 (3.1 per 1,000) children have been identified with CP.[3] In the United States, the ADDM tracked CP prevalence data in Alabama, Georgia, Missouri, and Wisconsin. This 2008 report found that CP prevalence was higher in boys compared to girls. CP was also more common among Black children compared to

White and Hispanic children. Additionally, most children with CP (77.4%) were identified as having spastic CP.[3]

International Prevalence Rates of Children with Cerebral Palsy

Several internationally based studies have reported prevalence of CP from 1.5 to 4 per 1,000 live births.[13-17] A review conducted by European researchers established that CP prevalence was comparable among several countries. For example, CP in China was reported to be 1.6 per 1,000 children younger than 7 years.[11] The prevalence in Australia was 2.0-2.5 per 1,000 children, while in the United States (Mississippi) prevalence was 2.12 per 1,000 children.[11]

Disparities among Children with Cerebral Palsy

Studies have determined higher rates of CP among both black children and among low-birth weight children when compared to white children.[11,17,18] However among low birth weight infants, rates of CP were higher among white children while among normal weight infants, rates of CP were higher among black children.[17,18]

Prevalence of CP may also differ according to social class and socioeconomic status (SES). In the United Kingdom, the prevalence of CP at birth was 3.33 per 1,000 births in low SES quintile while the prevalence in the highest SES quintile was 2.08 per 1,000 births.[11] Wu and colleagues (2011) found that in the U.S., socioeconomic markers (maternal education, low insurance status, onset of prenatal care) were also associated with likelihood of CP.[18] The link between high CP prevalence rates in low SES and low birth weight might be further explained with the association between higher rates of low birth weight in low SES individuals.[11]

Additionally, Durkin and colleagues (2015) found that as SES (indicated by maternal education) increases, risk for CP decreases. However the authors also found that after controlling for racial differences in SES, black children were still more likely to have CP when compared to white children. Furthermore, once adjusted for maternal education, there were no changes in the prevalence of CP among black children.[19]

Functional Abilities in Children with Cerebral Palsy

The majority of the children with CP (58.2%) are able to walk independently.[3] Additionally, 11.3% could walk using a hand-held mobility device, 30% use a wheelchair, and 30.6% had little or no walking ability.[3,20] Results from ADDM found that black children were 1.7 times more likely to have limited or no walking ability than white children. Researchers also found that 41% of children with CP have limited crawling, walking, running, and playing ability. Furthermore, 31% need special equipment such as walkers or wheelchairs.[3] An individual's functional abilities may substantially decline if they do not receive rehabilitation or management services, in some cases going dropping a full Gross Motor Functional Classification System (GMFCS) level. Therefore, seeking management services such as orthopedic surgery, rehabilitation, and other developmental services are crucial in maintaining the child's functional ability.[20]

Motor Function Level and Obesity in Children with Cerebral Palsy

GMFCS is a validated instrument developed by Palisano and colleagues (1997) to classify individuals into five functional levels formed by functional limitations, dependency on mobility devices, wheeled mobility, and quality of movement.[21] Inter-rater reliability of the GMFCS was 0.75 for children 2-12 years and 0.55 for children below 2 years.[21] [See Appendix 2]

Although very limited, a few studies have found an association between overweight and obesity (measured by BMI) and GMFCS level in children with CP. Hurvitz and co-authors (2008) established that children with GMFCS level I-II (ambulatory children) had a higher prevalence of overweight and obesity when compared to children with GMFCS levels IV-V.[22] Similarly, Rogozinski and colleagues (2007) found that overweight and obesity were more prevalent in children with GMFCS levels I and II. Furthermore, children with GMFCS level II are twice as likely to become obese when compared to children classified at a higher impairment level (GMFCS level III).[4] Although these two studies have determined that obesity is higher among children with mild functional impairment, further research is necessary to establish this association.

Co-occurring Conditions

Many children with CP have co-occurring conditions. According to the ADDM site in metropolitan Atlanta, 60% of 8-year old children with CP were also diagnosed with another developmental disability.[3] About 41% of children with CP also had co-occurring epilepsy. Epilepsy rates were highest among children with CP who had little to no walking ability.[3] Nearly 7% of children with CP also were identified with autism spectrum disorder (ASD), which was highest among children with non-spastic CP.[3]

Nutritional Status in Children with Cerebral Palsy

Healthy nutrition and physical activity are important factors in preventing obesity. Since many children with CP have motor impairment that inhibits the amount and type of physical activity, their nutritional status has a considerable impact on their obesity status. However, children with CP are at an increased risk for nutritional impairment.[23] Factors

such as difficulty swallowing or chewing can lead to complications including malnutrition, dehydration, aspiration, and pneumonia.[23-25]

Lopes and colleagues (2013) are among the few researchers to have assessed nutritional status of children with CP using dietary intake, with no similar studies taking place in the United States. The authors verified dietary intake by using a 24-hour recall food frequency questionnaire among a Brazilian cohort. Results demonstrated that children with CP (2-12.8 years old) had lower than recommended carbohydrate intake, adequate protein intake, higher than recommended fat intake, and low intake of fruits and vegetables. Additionally, the authors assert that their findings establish the unbalanced nutritional status of children with CP.[23] These findings, specifically low fruit and vegetable intake in addition to high fat intake potentially has important implications as a risk factors of obesity in children with CP. However another study that also examined dietary intake in a group of children with spastic quadriplegic CP found lower daily energy intake when compared to a control group of children without CP.[26] There is nevertheless a paucity of research within the United States concerning nutritional status of children with CP and the effects of dietary intake on their weight.

Prevalence of Overweight & Obesity in Children with Cerebral Palsy

U.S. Prevalence Rates of Obesity in Children with Cerebral Palsy

The United States lacks a widespread surveillance system that tracks prevalence of CP and co-morbidities. Therefore, a true estimate of prevalence of obesity and overweight in children and adults with CP within the United States is difficult to establish. However several studies have attempted to establish prevalence rates in various subpopulations. Rogozinski and co-authors (2007) evaluated rates of overweight and

obesity evaluated at three time points (1994-1997, 1998-2002, and 2003-2004) were 7%, 14%, and 16.5%, respectively.[4] Researchers analyzed the relationship between the prevalence of obesity and overweight with CP and age, gender, physical classification of CP and the level of functioning using the Gross Motor Function Classification System (GMFCS). Patients with hemiplegic CP had a significant increase in obesity from the first to last time period (6.9% to 19.4%, respectively). Similarly patients with a GMFCS II level had a significant increase in obesity that ranged from 7.8% in the first time period to 21.1% in the last time period.[4]

Researchers at the University of Michigan found 18% of all subjects to be overweight while 10.9% were considered at risk for overweight, making 29.1% of all subjects with a BMI that was above the normal range.[22] Ambulatory children with CP were found to have a higher prevalence (33%) of overweight than non-ambulatory children with CP (21%). When compared to the general population, ambulatory children with CP demonstrates a higher prevalence of overweight.[22]

International Prevalence Rates of Obesity in Children with Cerebral Palsy

The prevalence of obesity and overweight in children with CP vary across populations. Prevalence rates of obesity and overweight across several countries have ranged from 14.6% to 17%.[27-29] Norwegian children who were born between 1996-2003 had an overweight and obesity rate of 16%.[27] Data which was extracted from the Norwegian CP Registry, demonstrated that feeding issues and poor growth to be common in children with CP and more so in children with most severe CP. Furthermore overweight and obesity were found to be more common in children with spastic bilateral CP.[27]

A study in South Korea which included 766 ambulatory patients, found BMI significantly increased as age also increased for 2-6 year olds and 13-19 year olds with BMI being significantly higher for males than females.[28] Separate researchers in South Korea also established that 17% of participants (n=1397) were obese and overweight.[29] Similar to the study by Rogozinski and colleagues (2007), the prevalence of obesity significantly increased throughout the time periods observed.[29]

Healthcare Costs

The majority of individuals with developmental disability require long term, usually lifelong care and services. An estimated lifetime cost for an individual with CP is $11.5 million.[30] The cost of medical care in the US reached $147 billion in 2008. Results from a study found that obesity can increase annual medical costs by $2,741 (in 2005).[31] The average total health expenditure for a child with obesity under private insurance is $3,743 compared to $1,108 for all children under private insurance.[32] Using a large Medicaid database, Kancherla and colleagues (2012) discovered that children with CP accumulated medical expenses that were $15,047 greater than children without CP. When examining children with CP and co-occurring intellectual disability (ID), these costs were $41,664 higher than children without CP or ID and $26,617 higher than children with CP and without ID.[33] While the cost of CP is already staggering, developing obesity as a secondary condition can place further financial burden on individuals with CP, their families, and the health insurance system.

National Survey of Children's Health

The National Survey of Children's Health (NSCH) is among the few nationally representative surveys collecting height and weight data for children with CP, allowing

researchers to study obesity prevalence and trends in this population. The 2011 to 2012 data collection cycle is the first cycle of the NSCH to collect any information regarding CP.

The NSCH, a component of the State and Local Area Integrated Telephone Survey (SLAITS), is sponsored by the Centers for Disease Control and Prevention (CDC) and Maternal and Child Health Bureau (MCHB). The NSCH provides data on the physical and mental health, access to health care, and family, school, neighborhood, and social environments of children ages, 0 to 17 years of age.[34] The survey design was stratified by state and sample type (landline or cell phone) and clustered by children within households. The NSCH includes typically developing children as well as CYSHCN, including those with CP.[34] For the 2011-2012 NSCH, data were collected (between February 2011 through June 2012) through cross-sectional telephone interviews of households with at least one resident child in all 50 states and District of Columbia. Random digit dialing was used to sample households with children below 18 years of age. For households with more than one child, one child was randomly selected. Respondents were a parent or guardian with the greatest knowledge of the child's health and health care information. A total of 95,677 (unweighted) child-level interviews were conducted with 1,800-2,200 interviews per state. The sample was weighted to be representative of all non-institutionalized children ages 0 to 17 years of age.[34]

SIGNIFICANCE

Gap statement

Obesity among children with CP is a complex public health problem that involves the interplay of multiple factors. Although a few studies have explored the nutritional status of children with CP, the vast majority of the literature has concentrated on feeding methods and feeding ability of these children. There is a deficit of research within the U.S. examining individual eating habits of children with CP and its association with overweight and obesity.

A goal stated in the Healthy People 2020 is to "promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities." (U.S. Department of Health and Human Services (USDHHS), 2012). This goal has profound importance for children with CP, because health promotion and disease prevention targeting individuals with disabilities is often neglected. The frequency of secondary health conditions among this population has consequently increased, which may have considerable repercussions in the general health, well-being, and health-related quality of life for CYSHCN.[35] The purpose of this study is to inform the knowledge gap of which foods children with CP are consuming, why they are consuming these foods, and how this subsequently affects their overweight and obesity status.

RESEARCH QUESTION AND STUDY AIMS

Research Questions

- What are the eating habits of children with cerebral palsy?
- Which eating habits among children with cerebral palsy are associated with overweight and obesity?

Specific Aims

1. Establish the prevalence of overweight and obesity in children with cerebral palsy in the United States using the National Survey of Children's Health.

2. Examine the nutritional characteristics among children with cerebral palsy.

3. Assess associations if any, of nutritional intake among children with cerebral palsy with overweight and obesity in an urban cohort.

Literature Review

OBESITY IN CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Children and youth with special health care needs (CYSHCN) are children who require health-related services distinct from those of typically developed children. CYSHCN may exhibit signs of chronic physical, developmental, emotional, or behavioral conditions.[1] According to the CYSHCN Screener, most CYSHCN experience one or more of the following characteristics in order to be classified as CYSHCN: use of medications prescribed by a doctor; has a routine need for medical, mental health or educational services; is limited in his or her ability to do things most children of the same age can do; uses specialized therapies such as physical, occupational or speech therapy; and gets treatment or counseling for an emotional, behavioral, or developmental problem.[36]

For children, normal weight is defined as 5th-84.9th percentiles; overweight is classified as BMI between 85th-94.9th percentiles; and obesity is classified as BMI greater than the 95th percentile.[37] The prevalence of obesity among children 6-11 years increased from 7% in 1980 to 17% in 2012.[38] According to the National Survey of Child Health, approximately 31.3% of children in the United States are overweight and obese, ranging from 22.1% (Utah) to 39.8% (Louisiana).[39] This significant increase in overweight and obesity among children in the general population also extends to CYSHCN. CYSHCN have an obesity rate of 22% compared to 16% of children without special needs.[40] Studies outside of the U.S. such as one conducted in Patagonia, Chile found similar results. CYSHCN in this region were 22.5% overweight and 11.7% obese.[41] Geographic and climatic elements in Patagonia such as freezing temperatures and short growing

seasons make it difficult to engage in physical activity and to access fresh fruits and vegetables.[41] Although this study was conducted in a rural population of Chile, results demonstrate that location and environmental factors play a substantial role in contributing to obesity and overweight, especially in CYSHCN.

With respect to Healthy 2010 health indicators, CYSHCN fared worse than typically developing children in regards to obesity, physical activity, household tobacco exposure, depressive symptomology, and emergency department arrivals.[42] Obesity in CYSHCN can lead to a number of secondary conditions similar to all populations, such as but not limited to asthma, sleep apneoa, orthopedic complications, non-alcoholic fatty liver, and type II diabetes.[43,44] Therefore overlooking obesity may result in secondary conditions that can complicate the child's primary diagnosis.

CYSHCN may have physical, emotional, and/or cognitive condition(s) preventing them from engaging in activities or obesity prevention efforts.[45] Because CYSHCN require health-related services that are different from typically developed children, CYSHCN will also require obesity prevention strategies and programs distinct from typically developed children. Although there is an abundance of interventions that focus on children in the general population, CYSHCN are a sub-population that is often neglected in such programs.[46] Studies have shown that participation in these programs lead to positive results in some CYSHCN. Parents of CYSHCN reported less hospital visits and illness-related absences from school after their children participated in a physical activity and nutrition based program geared specifically for children with intellectual disabilities or autism.[47,48]

Certain medications often used by CYSHCN can affect weight by changing appetite, food preferences, fluid retention, hormone production, or metabolism.[49] For example, atypical antipsychotics, usually prescribed for people with developmental delays to treat aggression, depression, or anxiety, have shown to cause weight gain. The same is true for antidepressants, which usually cause craving for carbohydrates and sweets. Studies also show that anticonvulsant medications used to manage epilepsy have increased weight by two BMI units in over half of participants.[44]

THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH FRAMEWORK: CONCEPTUAL FRAMEWORK GUIDING AIMS OF RESEARCH

The International Classification of Functioning, Disability, and Health Framework (ICF) model is relevant to how health professionals plan and implement interventions and research related to CYSHCN. The ICF was developed to demonstrate the interactive relationship between the health condition and contextual factors (environmental and personal factors). The two contextual factors influence various elements of the health condition that in turn influences personal dimensions (body structure & function, activity, and participation). [See Figure 1] A traditional point of view is that disability is inherently within a person however a new understanding of disability, as reflected in the ICF, indicates that disability is a social construct that involves the interaction between the individual and their community.[50,51] The model allows for people looking to improve activity and participation of children whose functioning abilities are vulnerable and are at risk for secondary conditions.[51]

Including environmental factors in the ICF makes it possible to consider environmental barriers and facilitators (i.e. - physical, social, and attitudinal) that make it either possible or difficult to complete daily actions. When considering environmental barriers and facilitators to feeding children with CP, it is important to consider family as the environment. When the family is recognized as a facilitating factor contributing to the child's nutritional well-being (through implementing family-centered service), the family can participate in identifying goals for feeding their child. Consequently, the family can feed their child with minimal difficulty.[51] In this study, functioning relates to the child's ability to engage in all stages of eating. Participation refers to the feeding method the child employs (whether they are able to feed themselves, are orally fed, require an assistive feeding device or feeding tube). A general assistive feeding device is a tool or aid that is used by an individual to facilitate feeding by mouth. Conversely, a feeding tube (i.e., gastrostomy tube) provides an individual with nutrition when they are unable to feed by mouth. Finally, the child's social environment indicates the parent/caregiver's role in eating and feeding.

RISK FOR CHRONIC DISEASE IN ADULTHOOD

Onset of Complications and Secondary Conditions in Adulthood

In applying the ICF framework, secondary conditions are considered personal factors that may contribute to obesity by influencing other factors such as eating habits, feeding ability, and feeding methods. At present, life expectancy for well-functioning individuals with CP is close to that of the general population. As these survival rates increase, the risk of developing chronic diseases also increases.[52] There has been a two to

threefold increase in coronary heart disease mortality in adults with CP when compared to the general population. Therefore due to motor impairment and sedentary behavior that are characteristic of individuals with CP, patients of CP are becoming increasingly at risk for muscle dysfunction and obesity-related cardiometabolic disease.[53]

Obesity may increase the risk of complications such as insulin resistance, glucose intolerance, dyslipidemia, cardiovascular disease (CVD), type II diabetes and hypertension.[54] If obesity in childhood continues into adulthood, this may lead to the aforementioned health problems, among others.[53] CVD is known to have many risk factors including: elevated total cholesterol, low high-density lipoprotein cholesterol, waist circumference, obesity, reduced aerobic fitness, reduced level of everyday physical activity and smoking.[52] A study conducted by van der Slot and colleagues (2013) found many risk factors of CVD present in a sample of young adults with CP, Furthermore, higher body fat was associated with an increased 10-year risk of developing CVD.[52]

Monitoring Obesity in Children with Cerebral Palsy

Although body mass index (BMI) is a validated method of characterizing obesity status in the general population, using BMI to categorize individuals with CP may be problematic. BMI usually does not differentiate between adipose tissues and muscle and is unable to identify individuals that are not obese with excess body fat. Therefore individuals with muscle atrophy and diminished bone density, both common among adults with CP, may have a normal BMI but still have excess body fat. Consequently, BMI is an inadequate measure of cardiometabolic health in individuals with CP.[53] However a previous study by Peterson and colleagues (2012) found that waist to hip ratio was a good predictor of cardio-metabolic risk in adults.[55] If the current method of

classifying overweight and obesity in children with CP using BMI is not capturing true overweight/obesity rates, under diagnosing is a possibility. Therefore, overweight/obesity among children with CP may actually be more prevalent than has been established.

NUTRTION ISSUES IN CHILDREN WITH CEREBRAL PALSY

Malnutrition in Children with Cerebral Palsy

Nutritional status in a child with CP is a result of their eating habits that can influence several factors such as feeding ability, feeding methods, and obesity/overweight status. Although CP primarily affects neurodevelopment, difficulties in growth and nutrition are also common. While children with CP are often at risk for obesity, many are also at risk for under nutrition. Typically, children with CP tend to be smaller and have poor nutrition.[56] Pediatric malnutrition, also referred to as under nutrition, is defined as an imbalance of recommended nutrient intake and actual consumption. This may lead to a deficit in energy, protein, and micronutrients eventually leading to problems in growth, development, and other adverse outcomes.[57] Undernutrition that contributes to stunted linear growth may ultimately result from inadequate feeding skills. A study of children with neurodisability found that 83% of the participants had never been assessed by a dietitian although the majority of these participants had feeding or nutrition related problems.[58] Undernutrition may also negatively affect the child's muscular, cardiac, respiratory and immune systems.[59]

Impact of Malnutrition in Children with Cerebral Palsy

Children most at risk for nutrition issues have had inadequate weight gain at a younger age, severe motor impairment, and feeding and swallowing difficulties.[56]

Inadequate food intake can affect the nutritional status of children with CP. Studies have found prevalence rates between 45-50% of undernourishment in children with CP.[60] In a Greek cohort, children with CP were found to be deficient in the following nutrients when compared to their healthy siblings: vitamin A, biotin, folate, vitamin K, copper, zinc and marginal deficiency in iron. Participants with CP also showed lower weight, BMI, percentage body fat, weight for age Z score and tricep skinfold.[61] These finding suggests that feeding habits occur at a family level and that adequate or inadequate energy intake for both the child with CP and their sibling may be dependent on family's feeding practices.[61]

Food processing issues, swallowing problems, requiring assistance during feeding times, and extended meal times are among the common feeding problems that impede food intake.[56] Furthermore, secondary health problems such as gastroesophageal reflux (GER) may contribute to calorie loss while decreased activity levels can lead to low energy expenditure.[56] A population based study in North America (U.S. and Canada) found that a large percentage of children with moderate to severe CP were malnourished, primarily characterized by low fat stores, diminished muscle mass, and decreased height.[59] However when Samson-Fang and co-authors (2002) compared study results to other similar studies, they found that their participants were shorter and lighter in comparison.[59] Low fat stores in children were also found to have a substantial effect on participation and increased health care use. Furthermore, children with low fat stores were more likely to have a greater amount of missed school days, hospitalizations, physician visits, days spent in bed, and inability to execute routine activities.[59]

Nutrition plays an important role in the general health and well-being of all children, including those with CP. Malnutrition can have serious unfavorable effects on physiology, motor function, neurological and psychological functioning and can be most detrimental in early development.[35] In addition to the vast range of physical impairments caused by malnutrition, undernourished children shows signs of reduced exploratory activity, attachment behavior (important for developing social-emotional ability), irritability, decreased activity, social interaction, apathy, learning, and quality of life. These characteristics can hence play a role in the child's ability to play, participate in school, or rehabilitation.[35]

FEEDING ABILTIES IN CHILDREN WITH CEREBRAL PALSY (FUNCTIONING)

Characterizing Feeding Issues in Children with Cerebral Palsy

Similar to typically developing children, nutrition and diet, along with physical activity, can significantly influence susceptibility to higher obesity and overweight rates among children with CP. However unlike typically developed children, children with CP may have activity limitations and feeding difficulties that may inhibit their engagement in obesity prevention activities.[27] When applying the ICF framework, the child's eating and feeding ability can impact their eating habits and subsequently obesity and overweight status.

Children with CP often have difficulty feeding. They are at increased risk for oral, pharyngeal, or oesophageal dysphagia (difficulty swallowing).[24] Buchholz (1996) describes the twofold purpose of eating: 1) for pleasure and 2) nutrition and hydration.

Accordingly, dysphagia describes the state when these two purposes are not being met safely and capably. In broad terms, dysphagia refers to impairment in both swallowing food and other facets of eating such as chewing which can lead to complications such as aspiration and vomiting while eating.[62,63] Many children that aspirate while eating may exhibit signs through coughing, choking, or gagging. However in some cases, food may infiltrate the lungs silently.[63]

Over 75% of CP patients have a symptom of dysphagia.[24] Dysphagia can subsequently cause malnutrition, dehydration, and respiratory complications. This difficulty in feeding can be draining on parents and/or caretakers that are responsible for feeding the child with CP.[24] The inability to manipulate food in the mouth and pharyngeal movements, may affect feeding time. Several studies have demonstrated that feeding a child with CP takes exorbitantly more time than a typically developing child.[60,64,65] Long feeding times may therefore have a significant impact on what parents choose to feed their child while subsequently affecting the child's nutritional status.

Characterizing Motor Issues in Children with Cerebral Palsy

Oral motor impairment can lead to the inability of the child to feed themselves as well as inability to request food and drink. In a sample of 49 children with CP, 90% had oral motor dysfunction and 36.2% were severely impaired, making them at risk for undernourishment.[24] Children with oral motor impairment were less likely to self-feed than those without oral motor involvement (88% vs. 46%, respectively).[66] They also experienced higher frequency of coughing or choking, more involvement in swallowing evaluation and feeding therapy, and began to eat solid foods at a later age when compared to children with CP that did not have oral motor involvement.[24]

Feeding problems are positively correlated with motor functioning in children with CP. Although feeding difficulty is an issue for all children with CP, it mostly affects children with high severity of motor impairment.[27] Dahlseng and colleagues (2012) investigated feeding ability of children with CP and found that 94% of children with GMFCS levels I-II were able to independently feed themselves compared to 15% of children with GMFCS levels IV-V.[27] Furthermore, 26% of participants were totally dependent on feeding assistance compared to only 1% of children with GMFCS levels I-II.[27] Weir and colleagues (2013) found similar results when examining the association between parent-reported ability of children with CP to eat different food textures and gross motor function ability.[67] The ability to eat complex textured foods (i.e.-lumpy, cut up foods) or all textures were greatest in children in GMFCS level I. This ability gradually decreased as GMFCS level or severity increased.[67] Although the association between feeding problems and motor functioning has been established, there is a paucity of research that explores the relationship between obesity and overweight and motor functioning in children with CP.

FEEDING METHODS IN CHILDREN WITH CEREBRAL PALSY (PARTICIPATION)

In the ICF framework, the interaction between the child's ability to participate in feeding themselves and factors such as feeding ability and personal factors influences their eating habits and obesity status. The feeding process usually includes gathering, preparation, ingestion, swallowing, and digestion of foods.[68] For children with CP, difficulties may arise when ingesting and swallowing food. The methods by which individuals eat their food may vary according to the degree of difficulty. For children

with less difficulty eating, oral feeding may be a likely option. However for those with more difficulty eating, enteral nutrition, such as feeding tubes or gastrostomy tubes (GT) are an alternative to oral feeding.[68] In extreme cases, when children are not able to absorb or ingest food orally or through GT for a prolonged period of time, parenteral feeding (calories delivered intravenously) is the preferred route.[69]

Children's feeding methods are an important determinant in the growth outcomes of children with CP. Children with CP are at high risk for growth failure when compared to typically developing children. There are nutritional and non-nutritional factors that affect growth in children with CP. Body fat percentage, muscle area, and oral motor function are crucial to both weight gain and linear growth.[68]

Little has been done to ascertain the food intake of children with CP. Duration of meals is often underestimated while 3-day dietary intakes are overestimated by parents/caregivers.[68] When feeding difficulties are present in a child with CP, GT may be an appropriate option. However GT are considered when the child experiences the following: dysphagia leading to under nutrition; aspiration with respiratory disease; inadequate fluid intake and/or rejecting oral medications, and extreme difficulty and stress during feeding.[68] GT ensures adequate nutrition is being given to the child. This procedure has proven to reduce the risk of aspiration and increase quality of life. It is however often recommended that it only be used if other treatments have failed.[60]

The introduction of a GT for feeding should be carefully considered.[70] Before a GT is placed, the child's nutritional status, swallowing and functional ability, airway and respiratory ability, epilepsy status, and gastrointestinal ability should all be evaluated by their healthcare providers.[68] Hurvitz and colleagues (2008) found 28% of their non-

ambulatory participants were fed using GT while Østensjø and co-authors (2003) found that 51% of study participants used an assistive device while eating.[22,71] Although there are many benefits to using this intervention for children who have feeding problems, GT feeding comes with certain complications. One such complication is overfeeding. Non-ambulant children with CP who have low energy expenditure are more at risk for overfeeding when compared to ambulant children with CP.[70]

Some parents/caregivers often feel guilty over their child requiring a GT as they find this a failure to properly feed their child. The placement of a GT also takes away the social aspect of the child eating with their families and the joy experienced by parents when feeding their child.[60] However, parents/caregivers found that information on the benefits of GT for their child, effects on everyday life, and the child's potential growth was helpful in considering this feeding option. A qualitative study that explored caregiver's perceptions of GT feeding found that most parents/caregivers had negative responses upon hearing their child would be placed for a GT.[60] Many stated they were in denial of the fact their child needed a GT placement or desired a delay in the GT placement until other options were considered. Among other responses to GT include parents asserting that GT were unnatural or abnormal, an additional disability, unnecessary, or that they merely wished their child were to eat orally.[60] However, despite many negative perceptions and reactions to GT placement, most caregivers were pleased with the results of the feeding tube after the placement.[60] Although many qualitative studies have explored parental perceptions of GT placement in their child with CP, more research is needed to explore the association between GT placement and overweight and obesity.

ROLE OF PARENTS/CAREGIVERS (ENVIRONMENT)

Stressors Related to Feeding Children with Cerebral Palsy

The ICF framework considers physical and social environment a contextual factor that influence the interaction between eating habits, feeding ability, and feeding methods. Children with CP often rely on parents and/or caregivers for assistance during feeding times, and are considered part of the child's social environment. Parents may frequently face difficulty adjusting to additional duties and stressors that are common when caring for a child with CP.[72] These stressors often involve the time required for feeding, the parent's ability to adequately nourish their child, other familial responsibilities that parents inevitably face, and the decision for GT placement[72]

Many studies have noted the extended amount of time that it may take to feed children with[56,60,72-75] Qualitative studies that explore parental perspectives on feeding their child found that the time required for feeding was indeed a substantial concern. Preparing food and feeding the child meant less time for other family members or for themselves.[72] Initial occurrence of feeding problems ranged from birth; after a critical incident such as an illness or hospitalization (after a relatively unproblematic period); and when weaning onto solid foods.[74] Parents described the pressure they experienced during mealtimes and the relief they feel after their child eats something after much resistance. Similar to food, parents expressed the difficulty they face when trying to give their child fluids and medications.[75] Despite the struggle, parents also expressed positive outlooks. Some found that the long duration of feeding time as an opportunity to spend more quality or special time with the child.[72,74] Furthermore many parents viewed the extra

tasks involved in taking care of their child with CP not as a burden but inevitable part of their lives.[72]

Concerns are often linked to an expectation parents have, which supports the importance of considering the priorities of parents to address stressors. More frequent concerns reported include standing/walking, stiffness, and transition into adult care.[72,76] Parents of children with spastic quadriplegia were more concerned about eating/drinking and communication therefore suggesting that parental concerns are related to their child's diagnosis.[76] Studies suggest that because of the high amounts of stress endured by parents of a child with CP, they have poorer health than parents of children with typical development.[77] In addition to stress, mothers with a child with CP exhibit greater signs of anxiety and depression compared to the female norm.[78] Parkes and co-authors (2009) also found that the child's emotional and behavioral symptoms were statistically significantly related to high parenting stress ($p < 0.001$).[77] Children with borderline to abnormal scores on the Total Difficulties Score (TDS) of the Child Health Questionnaire parent form had increased odds of having parents with high stress compared to those with a normal score on the TDS. Child psychological problems also remained statistically significant in relation to parental stress.[77]

Parental Perspectives Related to Gastrostomy Tube Placement

The decision to place a GT is often a difficult decision for most families.[60] Matuszczak and colleagues (2014) found that 14 families took from 7 days to 24 months (Mean=5 months) to make the decision about GT placement.[73] After the GT placement, most parents/caregivers (95.4%) had no regrets and expressed satisfaction with the results of the GT.[73] Although parents felt that using and living with a GT is tiring and time

consuming, they reported the following improvements after the GT placement: significant improvements in their own social functioning; a significant reduction in feeding times (mean from 3 hours 44 minutes [range, 30 minutes to 6 hours] to 1 hours 5 minutes [range, 10 minutes to 4 hours]). Furthermore, parents were overall less stressed and had less anxiety about their children's food intake.[73]

Despite these benefits, some parents also had negative perceptions of GT. In spite of high amounts of stress associated with oral feeding, many parents were still not willing to choose the surgical option over oral feeding.[74] Some viewed placing tubes as a failure on their part to meet the nutritional needs of their child.[74] Craig and co-authors (2013) discovered that even after GT placement parents often considered managing and passing the tube difficult, mainly due to their child pulling it out.[74] Parents also expressed concern over GT causing negative impacts on oral feeding such as language development, and soreness and irritation. Although parents were aware of the benefits of GT, many were opposed to the suggestion of its placement, viewing it as a medicalization of feeding, which denies their child of the social aspects of eating orally.[74] They were thus concerned that GT would take away from participation in school and family life. Parents also felt that taking away treats would be cruel to the child since different textures and tastes of food was an important aspect of eating.[74] They stated that even though GT are placed on their child, they usually use this methods as a back up, choosing to orally feed their child at least one meal. However parents felt that more information about GT would be beneficial when the option was first suggested by a health care professional.[74]

Social activities have changed for parents that have a child with CP with many finding it difficult to participate in social activities outside the home. Through qualitative

methods, Brotherton and colleagues (2007) established that parents find it challenging to engage in social activities such as taking family holidays due to restricted feeding times.[75] Furthermore they also found it difficult to feed their child outside of the home (i.e.- restaurants, cafes). They felt uncomfortable about others staring and in some instances were asked to feed their child elsewhere.[75] In many situations, divisions in the family forms since all members of the family are unable to leave the home at the same time. Going out for a meal is increasingly difficult because special preparation and equipment is required for children with CP. While meals were viewed as a social interaction, having a child with CP meant that either the parent or child were left out of a social meal.[72] Childcare is especially a problem for families that do not have supportive extended families who are willing to take care of a child with CP without the parents present.[75]

Difficulties in feeding children with CP have been addressed by interventions that target parents. Focusing on the parents' behavior consequently enables a behavior change in the family system therefore benefiting the child.[78] Increasing parental education, among others, improved mealtime skills and behaviors important for increasing oral intake. Additionally, caregivers/parents also sufficiently provided their child with appropriate instructions, prompts and consequences during meals. Children accepted food by mouth and allowed parents to clean their mouth at feeding time during the course of the intervention.[79] Other interventions found positive results such as improved communication and increased activity during interactions.[78]

Involvement of Health Care Professionals in Feeding Children with Cerebral Palsy

In addition to parental perspectives, Morrow and colleagues (2008) explored perspectives of health care professionals (HCP) to determine if disparities between groups exist.[72] Many differences did exist which may have serious implications for the health of the child. For instance, parents felt that HCPs put too much emphasis on weight. Furthermore, HCPs viewed parental duties as a burden while parents themselves thought it was a part of life or a source of joy to care for their child. HCPs maintained that they mostly experience resistance from parents about GTs. Parents also viewed socialization as an important factor in QOL when compared to health professionals.[72]

Parkes and co-authors (2009) assert that parents are a useful addition to the team of specialists caring for their child because they have knowledge of the emotional social well-being and needs of their child, especially since these domains are often overlooked by HCPs.[77] Therefore the family centered approach to care is essential for not only the child but parents as well.[77] Family centered care, which refers to parents instead of HCPs guiding the child's care, has become a "gold standard" in care for children with CP.[78]

Power Analysis

A preliminary study found that obese children had an average total energy intake of 2,520 kilocalories (kcal) while non-obese children had an average of 2,026 kcal, with a mean difference of 494 kcal (Gillis & Gillis, 2005). Since other studies have found that children with less severe motor function tend to be more obese than children with more severe motor function. (Rogozinski et al., 2007; Hurvitz et al., 2008;), when controlling for GMFCS level, the estimated mean difference will be 394 kcal. After estimating the standard deviation to be about 700, power analysis determined that a sample size of 41 in

each group is necessary to perform the unpaired t-test for Aims 1 and 2. Statistical power of 80% is obtained to determine a 0.56 effect size in the sample of 82.

SIGNIFICANCE OF THE PROPOSED RESEARCH

This research aims to determine which eating and feeding habits are associated with obesity and overweight within a population of children with CP. Attaining this knowledge may impact the following: 1) Based on findings, guide relevant obesity prevention interventions and programs specifically targeting children with CP 2) Inform health care professionals on the importance of incorporating obesity prevention strategies in the management of CP, in order to prevent secondary conditions 3) Facilitate collaborations between HCPs, parents/caregivers, through a family-centered approach in order to benefit the child's nutritional status and 4) Identify areas for future research.

References

1. McPherson M, Arango P, Fox H, et al. A New Definition of Children With Special Health Care Needs. *Pediatrics.* 1998;102(1):137-139.

2. Centers for Disease Control and Prevention [CDC]. Disability and Health. 2012; http://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html. Accessed June 1, 2016.

3. Christensen D, Van Naarden Braun K, Doernberg NS, et al. Prevalence of cerebral palsy, co□occurring autism spectrum disorders, and motor functioning–Autism and Developmental Disabilities Monitoring Network, USA, 2008. *Dev Med Child Neurol.* 2014;56(1):59-65.

4. Rogozinski BM, Davids JR, Davis RB, et al. Prevalence of obesity in ambulatory children with cerebral palsy. *J Bone Joint Surg Am.* 2007;89(11):2421-2426.

5. Donini LM, Savina C, Cannella C. Eating habits and appetite control in the elderly: the anorexia of aging. *Int Psychogeriatr.* 2003;15(01):73-87.

6. Minihan PM, Fitch SN, Must A. What does the epidemic of childhood obesity mean for children with special health care needs? *J Law Med Ethics.* 2007;35(1):61-77.

7. National Institute of Health [NIH]. Cerebral Palsy: Hope Through Research. 2013; http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm. Accessed June 1, 2016.

8. Bax M, Goldstein M, Rosenbaum P, et al. Proposed definition and classification of cerebral palsy, April 2005. *Dev Med Child Neurol.* 2005;47(08):571-576.

9. Koman LA, Smith BP, Shilt JS. Cerebral palsy. *The Lancet.* 2004;363(9421):1619-1631.

10. Kuban KCK, Leviton A. Cerebral Palsy. *N Engl J Med.* 1994;330(3):188-195.

11. Odding E, Roebroeck ME, Stam HJ. The epidemiology of cerebral palsy: Incidence, impairments and risk factors. *Disabil Rehabil.* 2006;28(4):183-191.

12. (Centers for Disease Control and Prevention [CDC]. Cerebral Palsy. 2015. Accessed 03-08-2015.

13. Arneson CL, Durkin MS, Benedict RE, et al. Prevalence of cerebral palsy: Autism and developmental disabilities monitoring network, three sites, United States, 2004. *Disabil Health J.* 2009;2(1):45-48.

14. Bhasin TK, Brocksen S, Avchen RN, Braun KVN. *Prevalence of four developmental disabilities among children aged 8 years: Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1996 and 2000.* US Department of Health and Human Services, Centers for Disease Control and Prevention; 2006.

15. Paneth N, Hong T, Korzeniewski S. The descriptive epidemiology of cerebral palsy. *Clin Perinatol.* 2006;33(2):251-267.

16. Johnson A. Prevalence and characteristics of children with cerebral palsy in Europe. *Dev Med Child Neurol.* 2002;44(09):633-640.

17. Winter S, Autry A, Boyle C, Yeargin-Allsopp M. Trends in the prevalence of cerebral palsy in a population-based study. *Pediatrics.* 2002;110(6):1220-1225.

18. Wu YW, Xing G, Fuentes-Afflick E, Danielson B, Smith LH, Gilbert WM. Racial, ethnic, and socioeconomic disparities in the prevalence of cerebral palsy. *Pediatrics.* 2011;127(3):e674-e681.

19. Durkin MS, Maenner MJ, Benedict RE, et al. The role of socio□economic status and perinatal factors in racial disparities in the risk of cerebral palsy. *Dev Med Child Neurol.* 2015;57(9):835-843.

20. Novak I. Evidence-based diagnosis, health care, and rehabilitation for children with cerebral palsy. *J Child Neurol.* 2014;29(8):1141-1156.

21. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Gross motor function classification system (GMFCS). *Dev Med Child Neurol.* 1997;39:214-223.

22. Hurvitz EA, Green LB, Hornyak JE, Khurana SR, Koch LG. Body mass index measures in children with cerebral palsy related to gross motor function classification: a clinic-based study. *Am J Phys Med Rehabil.* 2008;87(5):395-403.

23. Lopes PAC, Amancio OMS, Araújo RFC, Vitalle MSdS, Braga JAP. Food pattern and nutritional status of children with cerebral palsy. *Rev Paul Pediatr.* 2013;31(3):344-349.

24. Reilly S, Skuse D, Poblete X. Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: a community survey. *J Pediatr.* 1996;129(6):877-882.

25. Aurélio SR, Genaro KF, Macedo Filho ED. Comparative analysis of swallowing patterns between children with cerebral palsy and normal children. *Rev Bras Otorrinolaringol.* 2002;68(2):167-173.

26. Stallings VA, Zemel BS, Davies JC, Cronk CE, Charney EB. Energy expenditure of children and adolescents with severe disabilities: a cerebral palsy model. *Am J Clin Nutr.* 1996;64(4):627-634.

27. Dahlseng MO, Finbråten AK, Júlíusson PB, Skranes J, Andersen G, Vik T. Feeding problems, growth and nutritional status in children with cerebral palsy. ***Acta*** *Paediatr.* 2012;101(1):92-98.

28. Kwon DG, Kang SC, Chung CY, et al. Prevalence of obesity in ambulatory patients with cerebral palsy in the Korean population: a single institution's experience. *Clin Orthop Surg.* 2011;3(3):211-216.

29. Park E, Chang W, Park J, Yoo J, Kim S, Rha D-w. Childhood obesity in ambulatory children and adolescents with spastic cerebral palsy in Korea. *Neuropediatrics.* 2011;42(02):60-66.

30. Centers for Disease Control and Prevention [CDC]. Economic costs associated with mental retardation, cerebral palsy, hearing loss, and vision impairment--United States, 2003. *MMWR Morbidity and mortality weekly report.* 2004;53(3):57-59.

31. Cawley J, Meyerhoefer C. The medical care costs of obesity: an instrumental variables approach. *J Health Econ.* 2012;31(1):219-230.

32. Marder W, Chang S. Childhood obesity: costs, treatment patterns, disparities in care, and prevalent medical conditions. Thomson Medstat Research Brief New York; 2006.

33. Kancherla V, Amendah DD, Grosse SD, Yeargin-Allsopp M, Braun KVN. Medical expenditures attributable to cerebral palsy and intellectual disability among Medicaid-enrolled children. *Res Dev Disabil.* 2012;33(3):832-840.

34. Centers for Disease Control and Prevention [CDC]. National Survey of Children's Health. 2012; http://www.cdc.gov/nchs/data/slaits/2011nschquestionnaire.pdf. Accessed June 1, 2016.

35. Kuperminc MN, Stevenson RD. Growth and nutrition disorders in children with cerebral palsy. *Dev Disabil Res Rev.* 2008;14(2):137-146.

36. Bethell CD, Read, D., Stein, R. E., et al. . Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Acad Pediatr.* 2002;2(1):38–48.

37. Barlow SE. Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: summary report. *Pediatrics.* 2007;120 Suppl 4:S164-192.

38. Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of childhood and adult obesity in the United States, 2011-2012. *JAMA.* 2014;311(8):806-814.

39. National Survey of Children's Health [NSCH]. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health. 2011-2012; http://www.childhealthdata.org.

40. Centers for Disease Control and Prevention [CDC] Division of Birth Defects and Developmental Disabilities. Disability and Health. 2012; http://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html. Accessed 03/08/2013.

41. Velez JC, Fitzpatrick AL, Barbosa CI, Díaz M, Urzua M, Andrade AH. Nutritional status and obesity in children and young adults with disabilities in Punta Arenas, Patagonia, Chile. *Int J Rehabil Res.* 2008;31(4):305-313.

42. Ghandour RM, Grason HA, Schempf AH, et al. Healthy people 2010 leading health indicators: how children with special health care needs fared. *Am J Public Health Res.* 2013;103(6):e99-e106.

43. Rimmer JH, Rowland JL, Yamaki K. Obesity and secondary conditions in adolescents with disabilities: addressing the needs of an underserved population. *J Adolesc Health.* 2007;41(3):224-229.

44. Grondhuis S, Aman M. Overweight and obesity in youth with developmental disabilities: a call to action. *J Intellect Disabil Res.* 2014;58(9):787-799.

45. Feehan K, O'Neil ME, Abdalla D, et al. Factors influencing physical activity in children and youth with special health care needs: a pilot study. *Int J Pediatrs.* 2012;2012.

46. Rimmer JH. Promoting Inclusive Community-Based Obesity Prevention Programs for Children and Adolescents with Disabilities: The Why and How. *Child Obes.* 2011;7(3):177-184.

47. Hinckson EA, Dickinson A, Water T, Sands M, Penman L. Physical activity, dietary habits and overall health in overweight and obese children and youth with intellectual disability or autism. *Res Dev Disabil.* 2013;34(4):1170-1178.

48. Abeysekara P, Turchi R, O'Neil M. Obesity and children with special healthcare needs: special considerations for a special population. *Curr Opin Pediatr.* 2014;26(4):508-515.

49. Correll CU. Weight gain and metabolic effects of mood stabilizers and antipsychotics in pediatric bipolar disorder: a systematic review and pooled analysis of short-term trials. *J Am Acad Child Adolesc Psychiatry.* 2007;46(6):687-700.

50. Organization WH. *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY.* World Health Organization; 2007.

51. Rosenbaum P, Stewart D. The World Health Organization International Classification of Functioning, Disability, and Health: a model to guide clinical thinking, practice and research in the field of cerebral palsy. *Semin Pediatr Neurol.* 2004; 11(1):5-10.

52. van der Slot W, Roebroeck ME, Nieuwenhuijsen C, et al. Cardiovascular disease risk in adults with spastic bilateral cerebral palsy. *J Rehabil Med.* 2013;45(9):866-872.

53. Peterson M, Gordon P, Hurvitz E. Chronic disease risk among adults with cerebral palsy: the role of premature sarcopoenia, obesity and sedentary behaviour. *Obes Rev.* 2013;14(2):171-182.

54. National Institutes of Health [NIH]. Executive Summary of the Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults. *Arch Intern Med.* 1998;158(17):1855-1867.

55. Peterson MD, Haapala HJ, Hurvitz EA. Predictors of cardiometabolic risk among adults with cerebral palsy. *Arch Phys Med Rehabil.* 2012;93(5):816-821.

56. Rempel G. The importance of good nutrition in children with cerebral palsy. *Phys Med Rehabil Clin N Am.* 2015;26(1):39-56.

57. Mehta NM, Corkins MR, Lyman B, et al. Defining pediatric malnutrition a paradigm shift toward etiology-related definitions. *JPEN J Parenter Enteral Nutr.* 2013;37(4):460-481.

58. Hartley H, Thomas JE. Current practice in the management of children with cerebral palsy: a national survey of paediatric dietitians. *J Hum Nutr Diet.* 2003;16(4):219-224.

59. Samson-Fang L, Fung E, Stallings VA, et al. Relationship of nutritional status to health and societal participation in children with cerebral palsy. *J Pediatr.* 2002;141(5):637-643.

60. Petersen MC, Kedia S, Davis P, Newman L, Temple C. Eating and feeding are not the same: caregivers' perceptions of gastrostomy feeding for children with cerebral palsy. *Dev Med Child Neurol.* 2006;48(09):713-717.

61. Grammatikopoulou MG, Daskalou E, Tsigga M. Diet, feeding practices, and anthropometry of children and adolescents with cerebral palsy and their siblings. *Nutrition.* 2009;25(6):620-626.

62. Buchholz DW. What is dysphagia? *Dysphagia.* 1996;11(1):23-24.

63. Gisel EG, Applegate-Ferrante T, Benson J, Bosma JF. Oral-motor skills following sensorimotor therapy in two groups of moderately dysphagic children with cerebral palsy: aspiration vs nonaspiration. *Dysphagia.* 1996;11(1):59-71.

64. Johnson CB, Deitz JC. Time use of mothers with preschool children: a pilot study. *Am J Occup Thery.* 1985;39(9):578.

65. Gisel E, Patrick J. Identification of children with cerebral palsy unable to maintain a normal nutritional state. *The Lancet.* 1988;331(8580):283-286.

66. Wilson EM, Hustad KC. Early feeding abilities in children with cerebral palsy: a parental report study. *J Med Speech Lang Pathol.* 2009:nihpa57357.

67. Weir KA, Bell KL, Caristo F, et al. Reported eating ability of young children with cerebral palsy: is there an association with gross motor function? *Arch Phys Med Rehabil.* 2013;94(3):495-502.

68. Rogers B. Feeding method and health outcomes of children with cerebral palsy. *J Pediatr.* 2004;145(2):S28-S32.

69. Aquilina A, Bisson R, Brennan J, et al. Guidelines for the Administration of Enteral and Parenteral Nutrition in Paediatrics. *Toronto: SickKids.* 2012.

70. Sullivan P. Nutrition and growth in children with cerebral palsy: setting the scene. *Eur J Clin Nutr.* 2013;67:S3-S4.

71. Østensjø S, Carlberg EB, Vøllestad NK. Everyday functioning in young children with cerebral palsy: functional skills, caregiver assistance, and modifications of the environment. *Dev Med Child Neurol.* 2003;45(09):603-612.

72. Morrow AM, Quine S, Loughlin EVO, Craig JC. Different priorities: a comparison of parents' and health professionals' perceptions of quality of life in quadriplegic cerebral palsy. *Arch Dis Child.* 2008;93(2):119-125.

73. Matuszczak E, Hermanowicz A, Klek S, et al. Parents' Perceptions of Gastrostomy Feeding for Children With Neurological Disabilities: A Multicenter Study. *J Hosp Palliat Nursg.* 2014;16(8):521-525.

74. Craig GM, Scambler G, Spitz L. Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support. *Dev Med Child Neurol.* 2003;45(3):183-188.

75. Brotherton AM, Abbott J, Aggett PJ. The impact of percutaneous endoscopic gastrostomy feeding in children; the parental perspective. *Child Care Health Dev.* 2007;33(5):539-546.

76. Knox V. Do parents of children with cerebral palsy express different concerns in relation to their child's type of cerebral palsy, age and level of disability? *Physiotherapy.* 2008;94(1):56-62.

77. Parkes J, McCullough N, Madden A, McCahey E. The health of children with cerebral palsy and stress in their parents. *J Adv Nurs.* 2009;65(11):2311-2323.

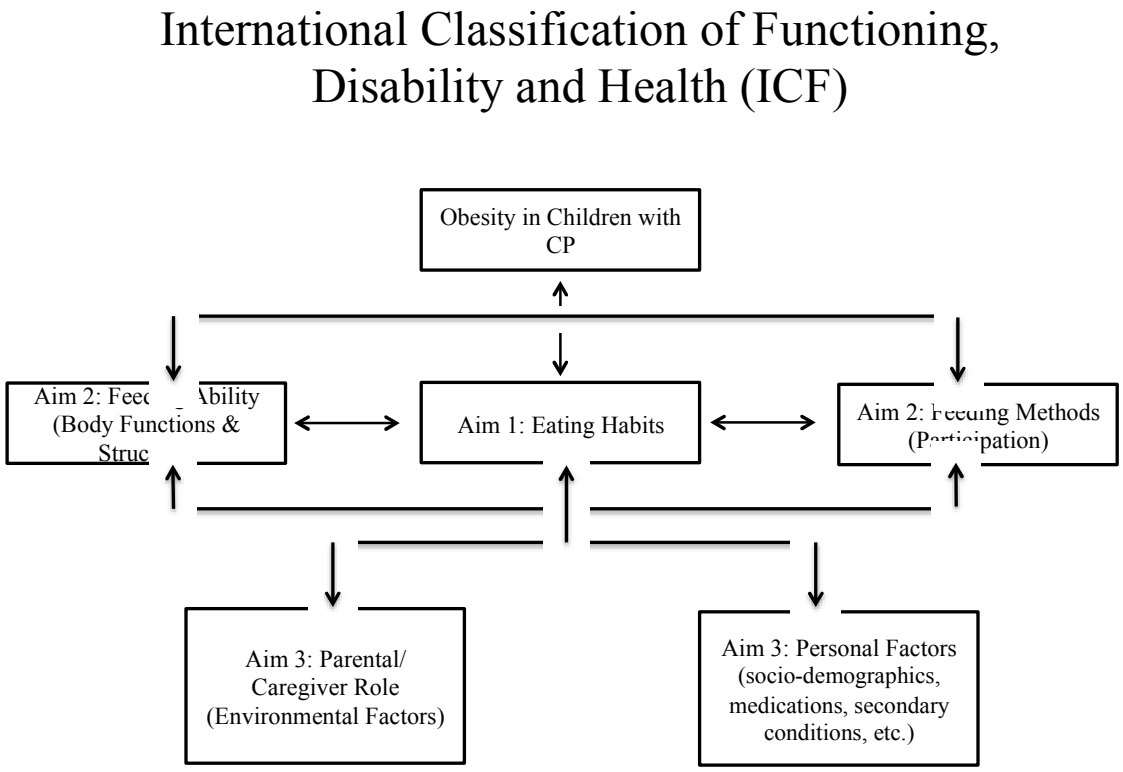
78. Whittingham K, Wee D, Boyd R. Systematic review of the efficacy of parenting interventions for children with cerebral palsy. *Child Care Health Dev.* 2011;37(4):475-483.

79. Clawson EP, Kuchinski KS, Bach R. Use of behavioral interventions and parent education to address feeding difficulties in young children with spastic diplegic cerebral palsy. *NeuroRehabilitation.* 2007;22(5):397.

80. Gillis L, Kennedy L, Gillis A, Bar-Or O. Relationship between juvenile obesity, dietary energy and fat intake and physical activity. *Int J Obes Relat Metab Disord.* 2002;26(4):458-463.

Appendix

Figure 1.



World Health Organization. (2002). Towards a Common Language for Functioning, Disability and Health: ICF. *Available at: www3. who.int/icf/beginners/bg.pdf.*

Prevalence of Overweight and Obesity in Children with Cerebral Palsy in the United States using the National Survey of Children's Health (NCHS)

Abstract

Background/Purpose: Cerebral palsy (CP) is the most common cause of physical disability in children. Obesity is an emerging problem for children with special needs including children with CP. The United States lacks a widespread surveillance system to track prevalence of CP and co-morbidities. Hence, we sought to establish the prevalence of obesity in the US among children with CP using nationally representative data from the NSCH. *Methods:* Data were obtained from the 2011-2012 NSCH. The NSCH provides data on the healthcare of children ages 0 to 17 years of age. Data included a total of 95,677 (unweighted) child-level interviews. The analytic sample included 312 children with CP, with sampling weights applied. Logistic regression was used to assess the prevalence of overweight/obesity in children with CP by calculating adjusted odds ratios (AOR) with 95% confidence interval (CI). *Results:* The prevalence of overweight/obesity was 26.8% in children with CP versus 31.3% in children without CP. Among children with CP, boys [AOR: 7.43 (95% CI: 2.42-22.76) were more likely to be overweight/obese compared to girls. Children with CP who walked independently were more likely to be overweight/obese than children who walked with assistance or did not walk (AOR: 3.31 (95% CI: 0.84-13.03)]. *Conclusion:* While our findings did not show a significant difference between children with and without CP and overweight/obesity status, our findings suggest that overweight/obesity should still be monitored in children with CP because more than one quarter of children with CP were overweight/obesity.

Introduction

Obesity has been a major public health concern among children in the United States (US) over the past few decades. The prevalence of obesity in children ages 6 to 11 years of age, has increased from 7% in 1980 to 17% in 2012.[1] It is also an emerging problem for children and youth with special health care needs (CYSHCN). Twenty-two percent of CYSHCN are obese, making rates in CYSHCN greater than typically developed children in the US.[2] Obesity in CYSHCN, including children with developmental disabilities, leads to a number of secondary conditions similar to all populations, such as asthma, sleep apnea, orthopedic complications, non-alcoholic fatty liver, and type II diabetes.[3,4] These concurrent health conditions may carry an additional burden on the already diminished social, physical, and mental health of CYSHCN.[5] However, there is a paucity of research establishing trends in obesity in CYSHCN, especially children with cerebral palsy (CP) in the United States.

Cerebral palsy is the most common cause of physical disability in children. Approximately 1 in 323 (3.1 per 1,000) children in the United States are diagnosed with CP.[6] Cerebral palsy is a permanent group of non-progressive neurological disorders, which occurs either in utero or post-natally, and is usually diagnosed in early infancy or childhood. Individuals with CP usually exhibit problems with muscle coordination and body movement.[7] Among children with CP, issues with body movement and muscle coordination often co-occur with visual, hearing, cognitive, and behavioral impairments.[8]

The risk of CP is associated with both social and biomedical factors. This assumption has been supported by studies that have found maternal age (< 20 years and >35 years), high parity in the mother, and low social class to be among the factors related

to CP.[9-14] Furthermore, researchers utilizing the Autism and Developmental Disabilities Monitoring (ADDM) Network reported higher prevalence of CP among boys (male/female, 1.4:1 ratio) and non-Hispanic Blacks, with rates up to 50% greater than non-Hispanic White.[6,14-18]

Comorbidities in children with CP can vastly affect their well-being and quality of life. Frequently documented comorbidities in children with CP include visual impairment, hearing impairment, intellectual disability, and epilepsy.[19,20] Although the Centers for Disease Control and Prevention (CDC) monitors CP through the ADDM Network, the United States lacks a widespread surveillance system tracking prevalence of CP and co-morbidities. Unfortunately, ADDM does not collect anthropometric data (e.g., height and weight) among children with CP, therefore precluding estimates of obesity prevalence.[21] Furthermore, as recent as 2014, the ADDM network monitors CP data only in four states in the United States (Alabama, Georgia, Missouri, and Wisconsin). Therefore, an accurate estimate of prevalence of obesity and overweight in children with CP in the United States has not been established.[21]

Current obesity rates come from several studies attempting to determine prevalence rates in smaller samples of children with CP. Estimated rates of overweight and obesity from a longitudinal study of children with CP progressively increased from 7% to 16% within a decade.[22] This study also reported patients with mild-moderate gross motor function impairment and hemiplegic CP experienced a significant increase in obesity across the ten-year period.[22] Hurvitz and colleagues (2008) found approximately 29.1% of children with CP had a

BMI above the normal range.[23] Similarly, Sison-Williamson et al. (2014) reported 36% of their sample being overweight and obesity.[24]

The National Survey of Children's Health (NSCH) is among the few nationally representative surveys collecting height and weight data for children with CP, allowing researchers to study obesity prevalence and trends in this population. The 2011 to 2012 data collection cycle is the first cycle of the NSCH to collect any information regarding CP. Therefore, the purpose of this study was to establish the national prevalence of obesity in the United States among children with CP using these data from the National Survey of Children's Health (NSCH).

Methods

Study Design and Sample Procedures

The NSCH, a component of the State and Local Area Integrated Telephone Survey (SLAITS), is sponsored by the Centers for Disease Control and Prevention (CDC) and Maternal and Child Health Bureau (MCHB). The NSCH provides data on the physical and mental health, access to health care, and family, school, neighborhood, and social environments of children ages 0 to 17 years.[25] The survey design was stratified by state and sample type (landline or cell phone) and clustered by children within households. The NSCH includes typically developing children as well as CYSHCN, including those with CP.[25] For the 2011-2012 NSCH, data were collected (between February 2011 through June 2012) through cross-sectional telephone interviews of households with at least one resident child in all 50 states and District of Columbia. Random digit dialing was used to sample households with children below 18 years of age. For households with more than one child, one child was randomly selected.

Respondents were a parent or guardian with the greatest knowledge of the child's health and health care information. A total of 95,677 (unweighted) child-level interviews were conducted with 1,800-2,200 interviews per state. The sample was weighted to be representative of all non-institutionalized children ages 0 to 17 years of age.

Measures

Cerebral Palsy. To establish whether the child has CP, respondents were asked: "*Has a doctor or other health care provider ever told you that your child has cerebral palsy?,* with a ' Yes' or 'No' answer choice.

Body Mass Index. Children's body mass index (BMI) was calculated using parental reported height and weight. Unlike adults, BMI calculations in children are reported as a percentile while taking into consideration age and sex. According to CDC growth charts, BMI is classified as: Underweight (<5th percentile); Normal or Healthy weight (5-85th percentile); Overweight (85th-95th percentile); and Obese (>95th percentile).[26] Although overweight and obese are two separate BMI categories, for analyses, the two categories were collapsed into one category (overweight/obese) to increase our statistical power. The clinical significance of separating overweight and obese categories are not of importance in this specific study, since overweight and obesity have similar etiology and risk factors.[27]

Covariates. Potential predictors that are associated with both overweight and obesity in children and CP include childhood demographic, socioeconomic, and individual characteristics. The child's demographic characteristics include child's sex, age, and race. In addition to childhood demographics, mother's parity (number of times mother has given birth) was also assessed.

Indicators of socioeconomic status include: poverty level, health insurance, and mother's education. Poverty level in the NSCH was defined by the U.S. Department of Health and Human Services (USDHHS) Poverty Guidelines.[28] Since most children with CP experience motor impairments, walking ability was also included as a covariate. Walking ability was assessed by asking whether the child walks without aid, walks with aid, or does not walk. Although not included in the multivariate models, this study examines the distribution of certain comorbidities in children with CP including: autism, developmental disability, intellectual disability, speech impairment, epilepsy/seizure conditions, hearing impairment, vision impairment, bone/joint/muscle impairment, and brain injury. From the comorbidities included in the NSCH, we considered the aforementioned comorbidities because they are clinically associated with individuals diagnosed with CP.

Missing Data

From the overall sample of 312 children with CP in the NSCH, 129 participants were missing either height and/or weight, which consequently made BMI unavailable for those children. Therefore, in the bivariate and multivariate analyses, the final unweighted sample excluded these children and was based upon 183 children with a calculated BMI.

Data Analysis

Statistical analyses were conducted using STATA software, version 14 (College Station, TX). Sampling weights were used to adjust for unequal selection probability that resulted from the cluster design. Sampling weights were applied to all analyses in this study.[29]

Children with and without CP

In bivariate analyses, χ^2 tests were used to compare children with and without CP on BMI and each of the following covariates: sex, age, race, health insurance, poverty level, parity, and mother's education. Ordinal logistic regression was used to estimate the crude odds ratio (OR) and 95% confidence intervals. The predictor variables of interest (Table 2) are CP status, sex, age, race, walkability, health insurance, poverty level, parity, and mother's education. The primary outcome variable of interest is BMI. For bivariate logistic regression, we separately assessed the association between each predictor variable (CP status, sex, age, race, walkability, health insurance, poverty level, parity, and mother's education) and the outcome variable (BMI). In multivariate analysis, adjusted odds of being overweight/obese (Table 2) in relation to possible confounding variables were run using ordinal logistic regression while adjusting for the following possible confounding variables: CP status, sex, age, race, poverty level, and parity.

Children with CP

We restricted the sample to only children with CP and examined the distribution of demographics, health insurance, parity, mother's education, and walkability, while stratifying by BMI (Table 3). The predictor variables of interest are sex, age, race, walkability, health insurance, poverty level, parity, and mother's education. The outcome variable of interest is BMI. For bivariate logistic regression (Table 5), we separately assessed each predictor variable (CP status, sex, age, race, walkability, poverty level, parity, and mother's education) and the outcome variable (BMI). For multivariate logistic regression (Table 5), we estimated adjusted odds of being overweight/obese in relation to possible confounding variables, by running an ordinal logistic regression while adjusting

for sex, age, race, walkability, poverty level, and parity in a subpopulation of children with CP.

Results

Children with and without CP

Participant characteristics comparing 312 (unweighted) children with CP to children without CP in the sample are presented in Table 1. The prevalence of CP was 2.6 per 1,000 children in the sample having been diagnosed with CP by a health care professional. The mean age of children with and without CP was comparable, 9.9 years and 9.6 years respectively. CP was more prevalent among males compared to females. The distribution of CP was also higher in Black children than White children. More than half (57%) of children with CP were at a healthy BMI and 26.8% were overweight or obese. Comparatively, 63% of children without CP had a healthy BMI while 31% were overweight or obese. Children with CP had a considerably higher percentage of underweight when compared to children without CP. Nearly all children with CP and without CP had some form of health insurance. There were no significant differences in parity and mother's education between the groups.

The results from bivariate and final multivariate odds models are presented in Table 2. In the unadjusted odds model, children with CP were less likely to be overweight or obese than children without CP [Odds Ratio (OR): 0.58 (95% CI: 0.26-1.33)]. However, this difference was not statistically significant. Unadjusted results also found mother's education to be significantly associated with overweight/obesity. Children were 2.4 (95% CI: 1.99-2.86) times as likely to be overweight/obese if their mother had less than a high school education when compared to mothers with at least

some college education. After adjustment for covariates, the odds of overweight and obesity for children with CP slightly decreased to 0.51 (95% CI: 0.22-1.21), with marginal significance, when compared to children without CP. After adjustment, males were 1.3 (95% CI: 1.16-1.39) as likely to be overweight and obese compared to females. Children ages 6-12 years were 1.4 (95% CI: 1.26-1.53) as likely to be overweight and obese when compared to older children. Black children were 1.4 (95% CI: 1.24-1.63) as likely to be overweight and obese as White children. Finally, children from a higher poverty level were 2.2 (95% CI: 2.01-2.58) times as likely to be overweight than children with a lower poverty level.

In the unadjusted model (Table 2) children with CP were more likely to be underweight than children without CP [OR: 1.7 (95% CI: 0.75-3.89)]. These results were not statistically significant. Unadjusted results also found mothers who had less than a high school education were less likely to have an underweight child compared to mother's with at least a college education [OR: 0.42 (95% CI: 0.35-0.50)]. After adjusting for covariates, children with CP were nearly twice as likely to be underweight than children with CP (95% CI: 0.83-4.55). Males were less likely to be underweight compared to females [OR: 0.79 (95% CI: 0.72-0.87)]. Adolescents (children ages 6-12 years) were also less likely to be underweight than older children (ages 13-18 years) [OR: 0.70 (95% CI: 0.67-0.82)]. Black children were also less likely to be underweight than White children [OR: 0.70 (95% CI: 0.61-0.80)]. After adjustment, children with health insurance had an increased odds of underweight compared to children without health insurance [OR: 1.28 (95% CI: 1.02-1.60)]. Finally, children with a higher poverty level

were 0.5 (95% CI: 0.40-0.51) times as likely to be underweight than children with a lower poverty level.

Children with CP

After restricting our sample to children with CP, we assessed the distribution of BMI while considering possible demographic and individual characteristics. [See Table 3] Predictors of sex, health insurance, and walkability were found to significantly vary by BMI level. Males in our sample had an overweight and obesity rate of 26.8% compared to only 6% of females. Approximately 27% of children with CP who had health insurance were overweight and obese compared to 10.7% of children that did not have health insurance. There was a significant difference in children who were underweight among children who had health insurance (14.8%) and children who did not have health insurance (65.3%). Children with CP who walked with no aid (27.1%) had comparable rates of overweight and obese to children that walked with an aid or did not walk (25.2%). However, rates of underweight were significantly higher in children that walked with an aid or did not walk (34.2%) when compared to children that walked with no aid (6.6%). Possible predictors of age, poverty level, mother's education, and parity did not significantly vary by BMI level as indicated by non-significant chi-square tests. However race varied by BMI with marginal significance.

The most common comorbidities for children with CP were developmental disability (90%), speech impairment (73%), and bone/joint/muscle impairment (65%). All comorbidities varied significantly by CP diagnosis. [See Table 4]

Results from unadjusted and final multivariate odds models among children with CP are presented in Table 5. In the unadjusted model, each covariate was considered in

relation to the child's BMI level (Underweight, Normal weight, Overweight/Obese). Males were 4.8 (95% CI: 1.85-12.76) times as likely to be overweight and obese than females. Children with CP whose mother had less than high school education were significantly less likely to be overweight/obese compared to children whose mothers with at least some college education [OR: 0.29; 95% CI: 0.10-0.87)]. The adjusted model included sex, child's age, race, walkability, and poverty level. Since 97.4% of children with CP had health insurance, we did not include this in our bivariate and adjusted models. Males with CP were 7.4 (95% CI: 2.42-22.76) times as likely to be overweight/obesity compared to their female counterparts. After adjusting for covariates, children who walked without an aid was 3.3 (95% CI: 0.84-13.03) times as likely to be overweight/obesity as children who walked with an aid or did not walk. The unadjusted odds of overweight/obesity in children from a higher poverty level were 1.3 (95% CI: 0.26-6.23) greater when compared to individuals with a lower poverty level. After adjusting for covariates, the odds of overweight/obesity increased for children from a higher poverty level [OR: 1.7 (95% CI: 0.41-7.02)]. There was only a significant difference in unadjusted and adjusted rates of overweight/obesity for sex and mother's education; all other covariates were not significantly associated with overweight and obesity.

Males with CP were 0.21 (95% CI: 0.08-0.54) times as likely to be underweight than females. Additionally, the odds of underweight was greater in children whose mother had less than high school education compared to children whose mothers with at least some college education [OR: 3.41; 95% CI: 1.16-10.11)]. After adjusting for

covariates, the odds of underweight in males further decreased [OR: 0.13; 95% CI: 0.04-0.41)]. All other covariates were not significantly associated with underweight.

Discussion

The prevalence of overweight and obesity in our sample is consistent with other studies that have established the rate of overweight and obesity among children with CP.[22-24] However, our results suggest that children with CP are as likely to be overweight or obese compared to children without CP. Despite not finding an association between overweight/obesity in children with CP, prevalence rates were nevertheless approaching those of children without CP, suggesting that children with CP are at similar risk for overweight/obesity as typically developed children. Understanding these trends might be useful in informing clinical approaches to preventing the onset of chronic conditions associated with overweight/obesity.

Although children without CP have a slightly higher rate of overweight and obesity in our study, results show that children with CP experience significantly higher rates of underweight and are at higher odds of being underweight when compared to children without CP. This may be explained by children with CP experiencing difficulty eating due to muscular abnormalities, problems such as dysphagia (difficulty swallowing) leading to malnutrition or inadequate weight gain.[30] Although the odds of being overweight/obese are not higher among children with CP, the rate of overweight/obesity found in our study is comparable to rates in the general population, signifying that overweight/obesity in children with CP is nevertheless an issue that should be clinically addressed.

When stratified by CP diagnosis, children with CP with the following characteristics had higher odds of being overweight/obese: boys, blacks, children with moderate to low poverty level, and parents with ≥2 pregnancies. Our study among children with CP is consistent with patterns found in other studies among the general population of children. Sex differences have been reported by other studies, with obesity being higher in boys than in girls.[1,31] Furthermore, studies have found Blacks and African American or Mexican-American and low-income households to have higher prevalence of overweight and obesity, a pattern consistent with our study.[1,32,33] Other recent studies echo trends found in our study such as findings that sex, income and race are risk factors of CP.[15,34,35] Although we study found that the risk of CP has been shown to increase with more pregnancies, other researchers have shown that nulliparity is also associated with CP.[9,10,36]

After adjustment, this study's analysis of BMI among children with CP found ambulatory children walking without any form of aid to have threefold increased odds of being overweight and obese. This finding is consistent with other literature suggesting ambulatory children have a higher prevalence of overweight/obesity than non-ambulatory children.[22,23] These studies posit that although ambulatory children are more likely to participate in physical activity, they are less likely to have difficulty eating therefore consuming greater amount of foods when compared to non-ambulatory children. However, other researchers found that non-ambulatory children with CP who have low energy expenditure are more at risk for overfeeding when compared to ambulatory children with CP.[37] These contradictory findings suggest further research needs to not

only explore risk factors in children with CP but also examine nuances possibly leading to overweight and obesity in both ambulatory and non-ambulatory children with CP.

Children with CP tend to have motor impairments possibly affecting their ability to eat certain foods. Many exhibit physical limitations making participating in physical activities difficult. For example, studies have found that children with CP were less physically activate and participate in less vigorous activities than children without any disability. Children with CP were more likely to participate in less vigorous activities for shorter amounts of time.[38,39] Furthermore, food processing issues, swallowing problems, requiring assistance during feeding times, and extended meal times are among the common feeding problems possibly impeding food intake.[30] Children with CP are inclined to be more selective with foods and may exhibit oral motor dysfunction where they are unable to chew and swallow certain textured foods.[40] These factors may lead to inadequate food intake, offering a possible explanation for why children with CP in our sample experienced higher rates of underweight.

Body mass index is the widely recommended method of assessing body composition in both adults and children. Although BMI has proven to be an effective method of identifying overweight and obesity in children, it does come with limitations, especially in our population of children with CP. Since CP affects motor functioning, calculating an accurate height and weight may be difficult with the inability to stand straight or lay down, which may explain the high percent of missing BMI data.

Several other limitations in our study are important to consider. First, only a small number of children with CP were assessed in the total sample. Since the 2011 to 2012 NSCH was the first to inquire about the child's CP diagnosis, previous cycles of the

NSCH could not be combined for analyses. Furthermore, although there were 312 children with CP, BMI was available for only 183 children. Therefore, in the regression models, our sample was restricted to 183 subjects or fewer when accounting for missing data. To solve this limitation, we conducted all analyses by weighting the survey data. The telephone survey was only conducted by parents, therefore although the question about CP diagnosis asked whether a doctor or health care provider made the diagnosis, this cannot be validated. Therefore, the actual percent of children with CP in the U.S. may be over or under-represented. Furthermore since this study as well as previous studies that have examined overweight and/or obesity in children with CP were cross sectional and therefore cannot infer causality, a longitudinal analysis would allow researchers to imply causality with overweight and obesity in children with CP.

Despite these limitations, our study has noteworthy strengths. The NSCH is a national sample that intends to be representative of all (non-institutionalized) children in the United States. This has been one of the first attempts to establish a national prevalence of obesity and overweight in children with CP in the United States, despite a lack of widespread surveillance of CP in the US Furthermore, our research adds to the literature, which is largely comprised of smaller studies.

Conclusion

While our results do not find a significant association between CP and overweight/obesity, the prevalence of overweight/obesity found in children with CP are nevertheless comparable to children without CP, thus revealing some insight into how the complex nature of CP may impact body weight. Therefore, since our results reveal that overweight/obesity is also an issue for children with CP similar to typically developed

children, prevention programs and interventions should also be adapted for this population. Since the NSCH is conducted every few years, this will allow future research to be focused on monitoring body weight in children with CP for longitudinal analyses. In addition to monitoring BMI in children with CP, understanding the intricacies behind the influence of feeding methods and abilities on the child's weight may lead to determining effective practices in preventing overweight and obesity in children with CP. With very little research on influences of nutrition and eating habits in children with CP, future research might assess how dietary intake may impact weight status in children with CP.

References

1. Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of childhood and adult obesity in the United States, 2011-2012. *JAMA.* 2014;311(8):806-814.

2. Centers for Disease Control and Prevention [CDC] DoBDaDD. Disability and Health. 2012; http://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html. Accessed June 1, 2016.

3. Rimmer JH, Rowland JL, Yamaki K. Obesity and secondary conditions in adolescents with disabilities: addressing the needs of an underserved population. *J Adolesc Health.* 2007;41(3):224-229.

4. Grondhuis S, Aman M. Overweight and obesity in youth with developmental disabilities: a call to action. *J Intellect Disabil Res.* 2014;58(9):787-799.

5. Rimmer J, Yamaki K, Lowry B, Wang E, Vogel L. Obesity and obesity□related secondary conditions in adolescents with intellectual/developmental disabilities. *J Intellect Disabil Res.* 2010;54(9):787-794.

6. Christensen D, Van Naarden Braun K, Doernberg NS, et al. Prevalence of cerebral palsy, co□occurring autism spectrum disorders, and motor functioning–Autism and Developmental Disabilities Monitoring Network, USA, 2008. *Dev Med Child Neurol.* 2014;56(1):59-65.

7. National Institute of Health [NIH]. Cerebral Palsy: Hope Through Research. 2013; http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm. Accessed June 1, 2016.

8. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl.* 2007;109:8-14.

9. Thorngren-Jerneck K. Cerebral injury in perinatal asphyxia. *Lund: Lund University.* 2002.

10. Topp M, Langhoff-Roos J, Uldall P. Preterm birth and cerebral palsy: predictive value of pregnancy complications, mode of delivery, and Apgar scores. *Acta Obstet Gynecol Scand.* 1997;76(9):843-848.

11. Dowding V, Barry C. Cerebral palsy: social class differences in prevalence in relation to birthweight and severity of disability. *J Epidemiol Community Health.* 1990;44(3):191-195.

12. Sundrum R, Logan S, Wallace A, Spencer N. Cerebral palsy and socioeconomic status: a retrospective cohort study. *Arch Dis Child.* 2005;90(1):15-18.

13. Dolk H, Pattenden S, Johnson A. Cerebral palsy, low birthweight and socio□ economic deprivation: inequalities in a major cause of childhood disability. *Paediatr Perinat Epidemiol.* 2001;15(4):359-363.

14. Wu YW, Xing G, Fuentes-Afflick E, Danielson B, Smith LH, Gilbert WM. Racial, ethnic, and socioeconomic disparities in the prevalence of cerebral palsy. *Pediatrics.* 2011;127(3):e674-e681.

15. Durkin MS, Maenner MJ, Benedict RE, et al. The role of socio□economic status and perinatal factors in racial disparities in the risk of cerebral palsy. *Dev Med Child Neurol.* 2015;57(9):835-843.

16. Maenner MJ, Benedict RE, Arneson CL, et al. Children with cerebral palsy: racial disparities in functional limitations. *Epidemiology.* 2012;23(1):35-43.

17. Yeargin-Allsopp M, Braun KVN, Doernberg NS, Benedict RE, Kirby RS, Durkin MS. Prevalence of cerebral palsy in 8-year-old children in three areas of the United States in 2002: a multisite collaboration. *Pediatrics.* 2008;121(3):547-554.

18. Arneson CL, Durkin MS, Benedict RE, et al. Prevalence of cerebral palsy: Autism and developmental disabilities monitoring network, three sites, United States, 2004. *Disabil Health J.* 2009;2(1):45-48.

19. Pruitt DW, Tsai T. Common medical comorbidities associated with cerebral palsy. *Phys Med Rehabil Clin N Am.* 2009;20(3):453-467.

20. Venkateswaran S, Shevell MI. Comorbidities and clinical determinants of outcome in children with spastic quadriplegic cerebral palsy. *Dev Med Child Neurol.* 2008;50(3):216-222.

21. Centers for Disease Control and Prevention [CDC], National Center on Birth Defects and Developmental Disabilities. Autism and Developmental Disabilities Monitoring (ADDM) Network. 2014; http://www.cdc.gov/ncbddd/autism/addm.html. Accessed September 15, 2016.

22. Rogozinski BM, Davids JR, Davis RB, et al. Prevalence of obesity in ambulatory children with cerebral palsy. *J Bone Joint Surg Am.* 2007;89(11):2421-2426.

23. Hurvitz EA, Green LB, Hornyak JE, Khurana SR, Koch LG. Body mass index measures in children with cerebral palsy related to gross motor function classification: a clinic-based study. *Am J Phys Med Rehabil.* 2008;87(5):395-403.

24. Sison-Williamson M, Bagley A, Gorton G, Johnson BA, Oeffinger D. Analysis of the relationships that body composition and muscular strength have with oxygen cost of walking in children with cerebral palsy. *Gait Posture.* 2014;40(4):628-632.

25. Centers for Disease Control and Prevention [CDC]. National Survey of Children's Health. 2012; http://www.cdc.gov/nchs/data/slaits/2011nschquestionnaire.pdf. Accessed June 1, 2016.

26. Kuczmarski RJ, Ogden CL, Guo SS, et al. 2000 CDC Growth Charts for the United States: methods and development. *Vital Health Stat 11.* 2002(246):1-190.

27. Maffeis C. Aetiology of overweight and obesity in children and adolescents. *Eur J Pediatr.* 2000;159(1):S35-S44.

28. U.S. Department of Health and Human Services [USDHHS]. Poverty Guidelines. 2016; https://aspe.hhs.gov/poverty-guidelines Accessed June 1,2016:

29. *Stata Statistical Software: Release 14* [computer program]. College Station, TX: StataCorp LP; 2015.

30. Rempel G. The importance of good nutrition in children with cerebral palsy. *Phys Med Rehabil Clin N Am.* 2015;26(1):39-56.

31. Meigen C, Keller A, Gausche R, et al. Secular trends in body mass index in German children and adolescents: a cross-sectional data analysis via CrescNet between 1999 and 2006. *Metabolism.* 2008;57(7):934-939.

32. Wang Y, Beydoun MA. The obesity epidemic in the United States—gender, age, socioeconomic, racial/ethnic, and geographic characteristics: a systematic review and meta-regression analysis. *Epidemiol Rev.* 2007;29(1):6-28.

33. Singh GK, Siahpush M, Kogan MD. Rising social inequalities in US childhood obesity, 2003–2007. *Ann Epidemiol.* 2010;20(1):40-52.

34. Solaski M, Majnemer A, Oskoui M. Contribution of socio□economic status on the prevalence of cerebral palsy: a systematic search and review. *Dev Med Child Neurol.* 2014;56(11):1043-1051.

35. Durkin MS. Socio□economic disparities and functional limitations of children with cerebral palsy. *Dev Med Child Neurol.* 2016;58(2):115-115.

36. Thorngren-Jerneck K, Herbst A. Perinatal factors associated with cerebral palsy in children born in Sweden. *Obstet Gynecol.* 2006;108(6):1499-1505.

37. Sullivan P. Nutrition and growth in children with cerebral palsy: setting the scene. *Eur J Clin Nutr.* 2013;67:S3-S4.

38. Bjornson KF, Belza B, Kartin D, Logsdon R, McLaughlin JF. Ambulatory physical activity performance in youth with cerebral palsy and youth who are developing typically. *Phys Ther.* 2007;87(3):248-257.

39. Maher CA, Williams MT, Olds T, Lane AE. Physical and sedentary activity in adolescents with cerebral palsy. *Dev Med Child Neurol.* 2007;49(6):450-457.

40. Reilly S, Skuse D, Poblete X. Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: a community survey. *J Pediatr.* 1996;129(6):877-882.

Appendix

Table 1. *Demographic characteristics of children with and without Cerebral Palsy*

	Children with CP (%) (n=312)	Children without CP (%) (n= 85,293)	p-value
CP Diagnosis	2.6 per 1,000 children		
Sex			0.2602
Male	38.4	51.2	
Female	61.4	48.7	
Age			0.7536
≤ 5 years	23.9	24.4	
6-12 years	40.6	43.9	
≥ 13 years	35.6	31.8	
Mean age (years):	*9.9 (SD: 5.32)*	*9.6 (SD: 4.58)*	
Race			0.0685
White	57.9	66.2	
Black	24.0	14.7	
Other	18.1	19.1	
BMI			0.0283*
Underweight	16.0	5.8	
Normal	57.2	62.9	
Overweight	14.9	15.6	
Obese	11.9	15.7	
Walkability			
No aid	55.3	-	
With aid/No walking	44.7	-	
Health Insurance			0.0238*
Yes	98.2	94.1	
No	1.8	5.7	
Poverty Level			0.0352*
≤150%	47.4	33.0	
>150%-300%	23.3	27.1	
>300	29.5	39.9	
Parity			0.4574
1 pregnancy	24.4	21.5	
2-4 pregnancies	75.7	78.5	
Maternal Education			0.8427
< High school	15.2	14.3	
High School	24.3	21.8	
> High School	60.6	63.9	

* $p<0.05$ Note: Walkability only asked in children with cerebral palsy

Table 2. *Unadjusted and Adjusted Model of Risk Factors of Overweight & Obesity in Children with Cerebral Palsy Compared to Children Without Cerebral Palsy*

Unweighted n=39,656 weighted n=28,505,621	**Overweight/Obese**		**Underweight**	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
CP Diagnosis	0.58 (0.26- 1.33)	0.51 (0.22-1.21)	1.71 (0.75-3.89)	1.94 (0.83-4.55)
Sex				
Male	1.27 (1.16-1.39)*	1.26 (1.14-1.39)*	0.79 (0.72-0.87)*	0.79 (0.72-0.86)*
Female	-ref-	-ref-	-ref-	-ref-
Age				
≤ 5 years	-	-		-
6-12 years	1.39 (1.26-1.53)*	1.35 (1.22-1.50)*	0.72 (0.65-0.79)*	0.74 (0.67-0.82)*
≥ 13 years	-ref-	-ref-	-ref-	-ref-
Race				
White	-ref-	-ref-	-ref-	-ref-
Black	1.66 (1.47-1.89)*	1.43 (1.24-1.63)*	0.60 (0.53-0.68)*	0.70 (0.61-0.80)*
Other	1.17 (1.0-1.37)*	0.99 (0.83-1.17)	0.86 (0.05-0.73)*	1.01 (0.86-1.20)
Health Insurance				
Yes	0.78 (0.62-0.98)*		1.28 (1.02-1.60)*	
No	-ref-		-ref-	
Poverty Level				
≤150%	2.29 (2.03- 2.58)*	2.21 (2.01-2.58)*	0.43 (0.39-0.49)*	0.45 (0.40-0.51)*
>150%-300%	1.46 (1.30-1.64)*	1.44 (1.28-1.61)*	0.69 (0.61-0.77)*	0.70 (0.62-0.78)*
>300%	-ref-	-ref-		-ref-
Parity				
1 pregnancy	-ref-	-ref-	-ref-	-ref-
≥2 pregnancies	0.91 (0.83-1.0)	0.83 (0.75-0.91)*	1.10 (0.04-1.00)*	1.20 (1.09-1.33)*
Maternal Education				
< High school	2.38 (1.99- 2.86)*		0.42 (0.35-0.50)*	
High School	1.61 (1.43-1.82)*		0.62 (0.55-0.70)*	
> High School	-ref-		-ref-	

* $p<0.05$

** Approaching significance ($p < 0.10$)

Notes: a) BMI not available or missing for children ≤9 years old. b) Mother's education not included in adjusted model. c) Health insurance was not included in the adjusted model as 95.6% of all children had health insurance. d) Adjusted for: CP status, sex, age, race, poverty level, and parity.

Table 3. *Characteristics of Children with Cerebral Palsy by BMI Classification*

	BMI Classification (%)				
n=183 weighted n=89,665	**Underweight (<5th %)**	**Healthy Weight (5th-85th%)**	**Overweight (85th-95th%)**	**Obese (>95th%)**	**p-value**
Sex					0.002*
Male	6.5	50.5	27.4	15.6	
Female	24.1	62.7	4.4	8.7	
Age					0.96
≤ 5 years	-	-	-	-	
6-12 years	17.5	53.7	17.2	11.6	
≥ 13 years	15.3	58.9	13.7	12.0	
Race					0.08
White	22.2	49.5	13.0	15.3	
Black	1.8	67.3	24.6	6.5	
Other	7.4	83.5	7.1	1.9	
Walkability					0.02*
No aid	6.6	66.3	16.5	10.6	
With aid/No walking	34.2	40.6	9.5	15.7	
Health Insurance					0.02*
Yes	14.8	58.0	15.2	12.0	
No	65.3	24.0	3.3	7.4	
Poverty Level					0.43
≤150%	23.7	42.2	17.1	17.0	
>150%-300%	6.6	66.9	19.5	6.9	
>300%	15.4	65.5	8.7	10.5	
Parity					0.21
1 pregnancy	9.6	72.0	8.0	10.5	
≥2 pregnancies	18.9	50.7	18.0	12.5	
Maternal Education					0.37
High School or less	9.5	66.3	7.0	17.2	
> High School	11.7	58.3	20.9	9.2	

* $p<0.05$

Note(s): a) Row percentages are reported b) All variables have a sample size of (n=183) with the following exceptions: Race (n=180); Poverty level (n=166); and Mom's Education (n=161). b) BMI not available or missing for children ≤9 years old.

Table 4. *Comorbidities in Children with Cerebral Palsy*

n=312 weighted n=171,660	Prevalence (%)
Developmental Disability	89.8*
Speech	73.1*
Bone, joint, muscle	65.0*
Intellectual Disability	47.2*
Epilepsy/seizure	41.2*
Brain Injury	38.4*
Vision	32.1*
Autism Spectrum Disorder	19.7*
Hearing	17.9*

*p <0.001

Table 5. *Unadjusted and Adjusted Model of Risk Factors for Overweight/Obesity in Children with CP*

	Overweight/Obese		Underweight	
Unweighted n=183 Weighted n=89,665	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Sex				
Male	4.86 (1.85-12.76)*	7.43 (2.42-22.76)*	0.21 (0.08-0.54)*	0.13 (0.04-0.41)*
Female	-ref-	-ref-	-ref-	-ref-
Age				
≤ 5 years	-	-	-	
6-12 years	1.03 (0.34-3.10)	0.85 (0.30-2.36)	0.97 (0.32-2.90)	1.18 (0.42-3.30)
≥ 13 years	-ref-	-ref-		-ref-
Race				
White	-ref-	-ref-	-ref-	
Black	1.85 (0.56-6.07)	1.66 (0.52-5.36)	0.54 (0.16-1.77)	0.60 (0.19-1.93)
Other	0.85 (0.32-2.29)	0.79 (0.22-2.93)	1.16 (0.44-3.10)	1.26 (0.34-4.65)
Walkability				
Without aid	2.43 (0.46-12.9)	3.31 (0.84-13.03)**	0.41 (0.10-1.67)	0.30 (0.08-1.19)**
With aid/No walking	-ref-	-ref-	-ref-	-ref-
Poverty Level				
≤150%	1.27 (0.26-6.23)	1.69 (0.41-7.02)	0.79 (0.16-3.90)	0.59 (0.14-2.43)
>150%-300%	1.55 (0.633-3.81)	1.73 (0.57-5.32)	0.64 (0.26-1.58)	0.58 (0.19-1.77)
>300%	-ref-	-ref-		-ref-
Parity				
1 pregnancy	-ref-	-ref-	-ref-	-ref-
≥2 pregnancies	1.13 (0.44-2.91)	0.96 (0.37-2.52)	1.13 (0.44-2.91)	1.04 (0.40-2.72)
Maternal Education				
< High school	0.29 (0.10-0.87)*		3.41 (1.16-10.11)*	
High School	1.60 (0.45-5.63)		0.63 (0.47-0.18)	
> High School	-ref-		-ref-	

* $p<0.05$

** Approaching significance ($p < 0.10$)

Note: a) Mother's education not included in adjusted model; b) Health insurance was not included in the adjusted model as 95.6% of all children had health insurance c) Adjusted for: sex, age, race, walkability, poverty level, and parity.

Nutritional Status and Food Intake of Children with Cerebral Palsy: A Descriptive Analysis

Abstract

Background/Purpose: Nutrition plays an important role in the general health and well-being of children with CP. Children with CP are often challenged with underweight, overweight and obesity, and short stature. Between 6-40% of children with CP were found to be undernourished while up to 29% of children with CP were overweight or obese. Feedings methods may be an important determinant in growth outcomes among children with CP. Therefore, the purpose of this study was to determine the nutritional status of children with cerebral palsy by examining their dietary intake, as many children with CP tend to experience nutrient imbalance. *Methods:* Cross-sectional parent-reported surveys of dietary intake and eating/drinking ability in children with CP were administered. Parents of children with a CP diagnosis, ages 2-18 years were recruited from a mid-sized urban children's hospital. The final analytic sample included children who orally consumed food (n=42). Means and standard deviations were used to calculate macronutrients, micronutrients, and food intake. A one-sample t-test was conducted to compare observed intake of macronutrients and micronutrients by age groups. *Results:* Mean carbohydrates, protein, total sugar, and total fat intake exceeded recommended daily intake across all age groups. Dietary fiber was below recommended intake levels across all age groups. Apart from cholesterol all macronutrients increased as the children aged until the 14-18 years, at which point intake decreased. Similarly, most micronutrients did not come close to recommended daily intake levels. While children with CP consumed fruits often, they did not consume vegetables, meats, fats, grains,

nut/legumes and sugars that often. *Conclusions*: We detected an overall unbalanced dietary pattern in children with CP that is high in fats, carbohydrates, protein, sugar and low in dietary fiber and vegetables. The difference between certain observed and recommended macronutrients and micronutrients widened until ages 14-18 years. Inadequate nutrient intake make lead to secondary chronic conditions. Therefore health care providers should focus on improving nutrient intake accounting for daily demands of children with CP.

Introduction

Cerebral palsy (CP) is the most common cause of physical disability in children. Cerebral palsy is a permanent group of non-progressive neurological disorders often affecting body movement, coordination and posture, and is usually diagnosed in early infancy or childhood.[1] Approximately 1 in 323 (3.1 per 1,000) children in the United States have been diagnosed with CP.[2] This wide-ranging disorder may often occur with intellectual, visual, hearing, cognitive, and behavioral impairments.[3]

Nutrition plays an important role in the general health and well-being of all children, including those with CP. Although CP primarily affects neurodevelopment, difficulties in growth and nutrition are also prevalent. Common nutrition-related challenges among children with CP include underweight, overweight and obesity, and short stature.[4,5] Between 6 to 40% of children with CP have been reported to be undernourished while up to 29% of children with CP have been reported to be overweight or obese.[6,7]

Unlike most typically developed children, children with CP may obtain their nutrients through feeding methods other than orally consuming their nutrients such as a gastrostomy tube (GT). Feeding methods are an important determinant in the growth outcomes of children with CP. Children with CP are at high risk for growth failure compared to typically developing children. There are nutritional and non-nutritional factors that affect growth in children with CP. Body fat percentage, muscle area, and oral motor function are crucial to both weight gain and linear growth.[8] Over 75% of individuals with CP have a symptom of dysphagia, which may lead to malnutrition,

dehydration, and respiratory complications.[9] Individuals with CP who exhibits symptoms of dysphagia (difficulty swallowing), are subsequently less likely to self-feed.[9,10] Hurvitz and colleagues (2008) found 28% of their non-ambulatory participants with CP were fed via GT, while Østensjø and co-authors (2003) found that 51% of their study participants with CP used an assistive device to facilitate feeding.[7,11]

Children with CP are often at-risk for feeding and swallowing difficulties leading to nutritional impairment or malnutrition.[12,13] Pediatric malnutrition is defined as "an imbalance between nutrient requirement and intake, resulting in cumulative deficits of energy, protein, or micronutrients that may negatively affect growth, development, and other relevant outcomes."[14] This may lead to a deficit in energy, protein, and micronutrient intake eventually leading to problems in growth, development, and other adverse outcomes (i.e., loss of functional status, infections, compromised immune system, etc.).[14] In addition to the vast range of physical impairments caused by malnutrition, malnourished children show signs of reduced exploratory activity, attachment behavior (important for developing social-emotional ability), irritability, decreased activity, social interaction, apathy, learning, and quality of life. Exploring risk factors of malnutrition specifically among children with CP, is vital because additional chronic conditions may complicate the child's existing conditions and quality of life.[15] However, while most researchers who study nutrition in children with CP have focused on malnutrition and growth, few studies have assessed dietary and nutrient intake. Therefore, the purpose of this study was to determine the nutritional status of children with CP by examining their dietary intake, because many children with CP tend to experience nutrient imbalance.

Methods

This study was approved by Drexel University's St. Christopher's Hospital for Children Institutional Review Board prior to any data collection. For this study, we collected cross-sectional parent-reported surveys of dietary intake in children with CP. Surveys administered to parents or legal guardians by the investigator included: demographics survey, National Health and Nutrition Examination Survey (NHANES) food frequency questionnaire (FFQ), Eating and Drinking Ability Classification System (EDACS) form, and a 24-hour dietary recall. Parents or legal guardians of children, ages 2-18 years old who were able to communicate in English were recruited from the Center for Children and Youth with Special Health Care Needs (CYSHCN) at St. Christopher's Hospital for Children, in a mid-sized urban children's hospital, located in Northern Philadelphia, Pennsylvania. Patients were identified for eligibility in the study by a CP diagnosis through electronic medical records. Parents were then approached for study enrollment during their child's clinic visit at the Center for CYSHCN. Written consent was subsequently obtained if parents decided to participate in the study. Parents completed the self-reported questionnaires (demographic questionnaire, NHAHES FFQ, EDACS form, and 24-hour dietary recall) in the exam room while they were waiting for the physician. Families were given a $15 gift card to a retail store as compensation for participating in the study.

Measures

Demographic Survey. Parents reported on their child and family socio-demographic characteristics (i.e. age, sex, household income, parental education, household size,

health insurance). Parents also reported on other characteristics relating to the child's CP diagnosis (CP type, physical activity ability, and sedentary behavior).

Cerebral palsy type refers to whether the child was hemiplegic, diplegic, monoplegic, or quadriplegic. Parents were questioned about their child's ability to participate in a physical activity and the length of time their child participated in screen time (i.e., television, computers, smart phones, iPads,) to assess sedentary behavior.

Body Mass Index. Children's body mass index (BMI) was collected through medical record abstraction. Unlike adults, BMI calculations in children are reported as a percentile while taking into consideration age and sex. According to CDC growth charts, BMI is classified as: Underweight (<5th percentile); Normal or Healthy weight (5-85th percentile); Overweight (85th-95th percentile); and Obese (>95th percentile).

Eating and Drinking Ability Classification System. The EDACS is a newly developed classification system that is used to evaluate eating and drinking abilities in children with CP. Eating and drinking performance was measured using five distinct levels, ranging from Level I, which refers to no limitations to safety and efficiency while eating to Level V, which refers to the most significant limitation to safety and efficiency while eating. [See Figure 1] The EDACS was found to be a valid and reliable system for measuring eating and drinking functioning among individuals with CP in both clinical and research settings.[16,17]

NHANES Food Frequency Questionnaire (FFQ). The NHANES FFQ was administered to parents to gain a comprehensive assessment of the child's frequency of dietary intake over the past 12 months, (FFQ). Some children with CP receive their nutrients through a gastrostomy tube (GT) if they have dysphagia and/or difficulty with chewing and

swallowing solid foods. In many cases, children with dysphagia will consequently consume liquid nutritional supplements (i.e., toddler or adult formulas) through a GT. Since most children who fed via a GT solely consume formula, a FFQ was only administered to parents with children who consumed non-formula foods.

Each item in the FFQ reported the child's frequency of consuming foods on a daily, weekly, monthly, or yearly basis. The respondent could choose from a total of 11 answer choices that ranged from 'Never' to '2 or more times per day.' Items in the FFQ were combined categorized to the following food groups: vegetables, fruits, meats, grains, nuts/legumes, sugars, milk, and juice. While solid foods in the FFQ were reported on a daily, weekly, monthly, and yearly basis, consumption of beverages were reported on a daily, weekly, and monthly basis only.

24-Hour Dietary Recall. Total energy, macronutrients, and micronutrients intake were measured using the 24-hour dietary recall method. Macronutrients included total dietary carbohydrate, protein, protein, dietary fiber, total sugar, total fat, saturated fat, and cholesterol. The micronutrients we chose to analyze were: iron, phosphorus, potassium, zinc, sodium, calcium, magnesium, vitamin A, vitamin C, vitamin E, vitamin B_6, vitamin B_{12}, vitamin D, vitamin K, thiamin, riboflavin, and folate.

Data Analysis

In the overall study, 84 patients gave consent to participate. The final analytic sample for this study was restricted to children who had a completed NHANES FFQ and 24-hour dietary recall (n=42). Approximately seven children who ate by mouth were unable to complete a 24-hour dietary recall; therefore, we could not assess calculate macronutrients and micronutrients for these participants. Our final sample size for dietary

intake was 35 children. In the overall study, 84 parents gave consent to participate. Approximately 10% of parents who were approached refused to participate. Although most participants who completed a NHANES FFQ consumed food orally, one participant consumed non-formula food through a GT; and therefore completed a NHANES FFQ and 24-hour dietary recall and was included in this analysis.

A descriptive analytics approach was used. Means and standard deviations were used to calculate mean daily nutrient intake of macronutrients and micronutrients. Since recommended levels of nutrients defined by the U.S. Department of Health and Human Services and U.S. Department of Agriculture are dependent on an individual's age, we stratified observed nutrient intake by age. Percentiles were used to calculate frequency of each food group in the FFQ. A one-sample t-test was conducted to compare observed intake of macronutrients and micronutrients to recommended levels of macronutrients and micronutrients. Analysis of the nutrition data from the 24-hour dietary recall was completed using FoodWorks® version 15 (The Nutrition Company, Long Valley, NJ). STATA software version 14 (StataCorp, College Station, TX) was used for all other data analysis.[18]

Scoring the NHANES FFQ involved summing items within each food groups (vegetables, fruits, meats, grains, nuts/legumes, sugars, milk, and juice) to calculate a raw score of intake frequencies. [See Figure 2] A higher score indicated increased consumption of the food group. The scores for the aforementioned food groups were then divided into quartiles based on the following Likert scale: seldom, sometimes, often, and very often. Since beverages were reported on daily, weekly, and monthly basis, we

divided these scores into tertiles. Frequency score for tertiles were based on the following Likert scale: seldom, sometimes, and often.

Results

Descriptive Characteristics

Table 1 presents social characteristics of children with CP in our study, ages 2 to 18 years of age who consumed food by mouth. The mean age of our sample was 8.2±5.5 years old. An equal percentage of our sample was male and female. The racial and ethnic composition of children in our sample was predominantly Non-Hispanic Black/African American. Most parents were low income (<$25,000), unemployed, and had obtained a college education, associate's degree, or graduated from trade school. Mean height of our sample was 43.3±11.6 inches with a mean weight of 63.0±42.08 pounds, with 58.5% of children within a healthy BMI percentile.

Approximately 32% of our sample had quadriplegia followed by hemiplegia (25.0%), diplegia (25.0%), and monoplegia (18.0%). The majority of children in our sample who were able to eat by mouth ate effectively and efficiently as depicted by the 41.5% of children in our sample classified as EDACS Level I. Over half of our sample was ambulatory; however, 40.5% used an electronic device (i.e., television, computer, iPad etc.) between one to three hours per day.

Macronutrients

Dietary intake of macronutrients along with recommended daily intakes based on the 2015 to 2020 Dietary Guidelines for Americans established by the U.S. Department of Health and Human Services (USDHHS) and the U.S. Department of Agriculture (USDA), is presented in Table 2. . Among children, 2 to 3 years of age, mean total energy

intake (1,120.6±381.8 kilocalories [kcal]) was slightly higher than the recommended level of 1,000 kcal for children of that age group. While the mean total energy intake for children, 4 to 8 years of age (1,318.6±296.8) and 9 to 13 years of age (1,767.4±494.7) was within the recommended level, the mean total energy intake for children, 14 to 18 years of age (1,570.2±555.4) was below recommended levels. Furthermore, increased mean carbohydrates, protein, and total sugar, and total fat intake exceeded recommendations across all age groups. Mean intake of dietary fiber across all age groups was lower than the recommended range of 14g among children 2 to 3 years of age; 16.8g-19.6g among children 4 to 8 years of age; 22.4g-25.2g among children 9 to 13 years of age; and 25.2g-30.8g among children 14 to 18 years of age.

Consumption of the majority of macronutrients (carbohydrates, dietary fiber, total sugar, protein, and saturated fat, total fat) increased as children with CP increased in age, until they reached 14 to 18 years of age, at which point consumption of these macronutrients decreased. However, observed cholesterol intake of children in our sample fluctuated between age groups. Among children 2 t o3 years of age, significant differences between observed intake and recommended levels were detected in protein, total sugar, and total fat intake. Among children 4 to 8 years of age, significant differences between observed intake and recommended levels were detected in carbohydrate, protein, total sugar, and total fat. Among children 9 to 13 years of age, significant differences between observed intake and recommended levels were detected in carbohydrate, protein, dietary fiber, total sugar, and total fat. Finally, among children 14 to 18 years of age, significant differences between observed intake and recommended

levels were detected in total caloric intake, carbohydrate, protein, dietary fiber, and total fat.

Micronutrients

Table 3 and Table 4 presents observed and recommended levels of minerals and vitamins, respectively, among our sample. Iron, phosphorus, zinc, sodium, vitamin c, vitamin B_6, vitamin B_{12}, magnesium, thiamin, riboflavin and folate were higher than the recommended daily intake for most age groups. Potassium and Vitamin E intake was significantly lower than recommended levels across all age groups. Vitamin A intake was also significantly lower than the recommended daily intake for all age groups, except children ages 4 to 8 years of age.

Similar to the pattern found in macronutrients, intake of several micronutrients increased as children with CP aged until as they increased in age, until 14 to 18 years of age. At that time, micronutrients decreased. Micronutrients displaying this aforementioned pattern include: iron, phosphorus, zinc, sodium, magnesium, vitamin E, vitamin B_6, thiamin, riboflavin, and folate. Intake of potassium, calcium, sodium, and vitamin B_{12}, gradually increased as children with CP got older. Finally, mean intake of vitamin A and vitamin C fluctuated as an increase in consumption of these vitamins was detected through 4 to 8 years of age, with a subsequent decrease at 9 to 13 years of age, followed by a subsequent increase at 14 to 18 years of age. Among children 2 t o3 years of age, significant differences between observed intake and recommended levels were detected in iron, phosphorus, potassium, zinc, magnesium, vitamin B_6, vitamin B_{12}, vitamin D, vitamin K, thiamin, riboflavin, and folate. Among children 4 to 8 years of age, significant differences between observed intake and recommended levels were detected

in iron, phosphorus, potassium, zinc, calcium, magnesium, vitamin c, vitamin B_6, vitamin B_{12}, vitamin D, thiamin, riboflavin, and folate. Among children 9 to 13 years of age, significant differences between observed intake and recommended levels were detected in iron, potassium, zinc, sodium, calcium, vitamin A, vitamin B_6, vitamin B_{12}, vitamin D, thiamin, and riboflavin. Finally, among children 14 to 18 years of age, significant potassium, calcium, vitamin B_{12}, vitamin D, thiamin, and riboflavin.

Food Frequency Questionnaire

We subsequently examined food-frequency data from the NHANES FFQ, presented in Table 5. Frequency of food intake scored using the NHANES FFQ was divided into quartiles (seldom, sometimes, often, very often) and beverage intake was divided into tertiles (seldom, often, very often). While participants sometimes consumed vegetables (56.8%) fruits (59.5%) were consumed often. Forty percent of participants sometimes ate grains. Meats (51%), fats (54%), and sugars (51%) were sometimes consumed. The majority of participants seldom consumed milk (70%) and sometimes consumed juice (43%).

Discussion

In this study, we examined food and nutrient intakes of children with CP, 2 to 18 years of age, who consumed food and beverages by mouth. Our sample was relatively young, predominantly Black/African, with low-income households (<$25,000 annually). The majority of children in our sample were ambulatory and within a healthy BMI percentile. Most children in our sample presented less difficulty in chewing and swallowing food, as reported through a higher percentage of children with EDACS Levels I and II.

Overall, our sample population showed an unbalanced dietary pattern high in carbohydrates, protein, fats and sugar, and low in dietary fiber and vegetables. The difference between observed and recommended daily intake of carbohydrates, total sugar, total fat, and total energy widened until children reached ages 14 to 18 years of age, at which point these older children were closer to reaching recommended daily intake of macronutrients. Similarly, the gap between observed and recommended daily intake of iron, phosphorus, zinc, thiamin, riboflavin, and folate were smallest in older children (14 to 18 years of age). Many foods are fortified with micronutrients such as thiamin, folate, and riboflavin. Therefore fortified foods may contribute to the increased intake of these micronutrients, if children in our sample are eating greater quantities of these foods. Additionally, reduced amounts of phosphorus and calcium may especially affect bone health in children with CP. Orthopedic complications such as osteoporosis may result since children with CP are prone to be weight bearing.

Finally, because most of our population represented households of lower income, it is possible that our participants are enrolled in the Women, Infants, and Children (WIC) federally funded program. Participants of the WIC program receive vouchers for supplemental foods such as milk, infant formula, cereal, etc.). While changes to the nutrition program were implemented in 2009 that intended to increase consumption of fruit and vegetable intake and reduced amounts of fat, cholesterol, and sugar intake, the increased amount of sugar in our sample may be due, in part, to children who consume infant formulas, which contain high amounts of sugar.

The common understanding that food selectivity decreases as children grow older may explain a more balanced nutrient intake among older children in our sample.

Beighley et al. (2013) concluded that atypically developed children, especially children with Autism Spectrum Disorder (ASD), were more food selective than typically developed children. This same group of researchers established that food selectivity among children with ASDs and pervasive developmental disorders decreased across childhood.[19] Although very little has been published on food selectivity in children with CP, similar trends found by Beighley and colleagues (2013) may be established in our sample because ASD and other developmental delays are often a comorbidity of CP.

Furthermore the racial composition at St. Christopher's Hospital for Children and the Center for CYSHCN is predominantly Black/African American and Hispanic. Rice and starchy vegetables such as potatoes and corn are often staple foods among the aforementioned racial/ethnic groups.[20,21] Rice contains high amounts of carbohydrates, even higher than breads and pasta. Furthermore vegetables high in starch increases total carbohydrates, explaining carbohydrate intake greater than recommended levels.

Chronic conditions (i.e., hypertension, diabetes, heart conditions, stroke, asthma, etc.) are generally higher and occur earlier among individuals with CP when compared to individuals without CP.[22] Intake of sodium above recommended dietary guidelines in our sample may indicate a high consumption of processed foods, which are frequently associated with higher incidence of hypertension, stroke, and heart disease.[23] The largely preventable nature of many of these chronic conditions raises an important question of whether nutrient intake in children with CP may influence chronic conditions related to one's diet (i.e., hypertension and diabetes mellitus), especially since mobility and functional impairment are concerns as individuals with CP ages.[22]

Improving knowledge and feeding practices among parents and caregivers of children with CP should be emphasized by health care providers. Although plans to improve nutritional status among their children are often discussed with a provider, parents' adherence to these plans may not always occur. Therefore, adherence to these healthier nutritional plans should be closely monitored, especially among children who are fed orally, since they consume a variety of foods and can consume greater portion sizes, unlike children who are formula fed. Furthermore, with predominantly families of low-income in our study, the lack of access to healthy foods may result in the inadequate nutrients among our sample. Despite nutritional programs designed for low-income families, food insecurity may inevitably be a barrier for families to acquire healthy foods for their child. Availability of healthy foods is associated with greater consumption of healthy products.[24] Giang et al. (2010) cited Philadelphia, Pennsylvania as experiencing a supermarket exodus over the past two decades, leaving many neighborhoods in the city with a shortage of access to healthy foods. Disparities between Philadelphia neighborhoods of high-income and low-income were substantially evident, with 156% more supermarkets in high-income areas when compared to low-income areas.[25] Inadequate nutrient intake among our sample of children with CP may go beyond their diagnosis and point to more pervasive disparities in access to healthy foods causing inadequate nutritional status in most individuals in North Philadelphia. Therefore, further research should target screening for food insecurity in populations of low-income similar to our sample of children with CP.

Insufficient nutrient levels may also in part be attributable to feeding complications, such as dysphagia or aspiration, which are often problems in children with

CP. Feeding difficulty may also limit food options, and thus, affect nutrient intake if children have problems chewing and swallowing certain foods.[26,27] Therefore, health care providers should focus on improving nutrient intake that is adequate for the daily demands of children with CP. In doing so, health care providers should establish the nutritional status of individual patients and subsequently engage in discussions with parents and/or caregivers on strategies to attain a more balanced diet. For example, health care providers can explore dietary modifications with their parents and caregivers of patients to suggest replacing processed foods with high sodium levels with more fresh home-cooked foods or replacing high sugar and fat snacks with fruits, vegetables, and grains.

Although intake of protein, total fat, and total sugar, as reported through the 24-hour dietary recall, exceed the recommended daily amount, frequency reported through the FFQ indicated contradictory results. For example, while the majority of respondents indicated that their child consumes sugar either seldom or sometimes, dietary intake through the 24-hour dietary recall indicated that the total sugar intake of children in our sample significantly surpassed the daily recommendation, implying that children in our sample consumed increased amounts of sugar. Consequently, response bias may be a limitation of our study if parents feel compelled to report higher intake of healthier foods and lower intake of un-healthy foods. Furthermore, due to the cross sectional nature of our study, we only collected the 24-hour dietary recall and FFQ at one time point; therefore, it is possible that in some cases the food reported was not necessarily indicative of most meals that the child consumed. It should also be noted that our study is limited by a small sample size. Furthermore, since our study was restricted to parents who were able

to speak English, we were unable to include many parents who communicated in Spanish. This may introduce selection bias since the dietary composition of many non-Spanish speaking families may vastly differ from Spanish speaking families. Lastly, our study is limited to children with similar ethnic, socioeconomic, and geographic characteristics. Therefore, our study may be less generalizable to other populations.

Despite these limitations, our study has notable strengths. To our knowledge, this is among the first studies to examine food and nutrient intake in a population of children with cerebral palsy in the United States. We believe that our results provide reasonable estimates of nutritional status and nutrient intake among children with CP. Furthermore, while most researchers have focused on how nutrition affects growth in children with CP, little focus has been given on what children with CP are consuming. Therefore, our study fills this gap in the literature by revealing typical nutrient consumption and deficiencies among children with CP.

Conclusion

In summary, our overall results indicated that the nutritional status of children with CP is inadequate. These findings may have clinical implications that involve implementing individualized education and interventions for parents and caregivers that would promote a well-balanced diet among their children with CP by using current recommendations to reach dietary goals. Furthermore, future research should utilize longitudinal methods to establish nutritional status in children with CP which would better reveal the child's general dietary intake, because cross-sectional data only provide insight into the child's nutrition at one point in time.

References

1. National Institute of Health [NIH]. Cerebral Palsy: Hope Through Research. 2013; http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm. Accessed June 1, 2016.

2. Christensen D, Van Naarden Braun K, Doernberg NS, et al. Prevalence of cerebral palsy, co□occurring autism spectrum disorders, and motor functioning–Autism and Developmental Disabilities Monitoring Network, USA, 2008. *Dev Med Child Neuro.* 2014;56(1):59-65.

3. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl.* 2007;109:8-14.

4. Ekvall VK. *Pediatric nutrition in chronic diseases and developmental disorders: prevention, assessment, and treatment.* Oxford University Press; 2005.

5. Yang Y, Lucas B, Feucht S. *Nutrition Interventions for Children with Special Health Care Needs.* Washington State Department of Health; 2010.

6. Joosten KF, Hulst JM. Prevalence of malnutrition in pediatric hospital patients. *Curr Opin Pediatr.* 2008;20(5):590-596.

7. Hurvitz EA, Green LB, Hornyak JE, Khurana SR, Koch LG. Body mass index measures in children with cerebral palsy related to gross motor function classification: a clinic-based study. *Am J Phys Med Rehabil.* 2008;87(5):395-403.

8. Rogers B. Feeding method and health outcomes of children with cerebral palsy. *J Pediatr.* 2004;145(2):S28-S32.

9. Reilly S, Skuse D, Poblete X. Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: a community survey. *J Pediatr.* 1996;129(6):877-882.

10. Wilson EM, Hustad KC. Early feeding abilities in children with cerebral palsy: a parental report study. *J Med Speech Lang Pathol.* 2009:nihpa57357.

11. Østensjø S, Carlberg EB, Vøllestad NK. Everyday functioning in young children with cerebral palsy: functional skills, caregiver assistance, and modifications of the environment. *Dev Med Child Neurol.* 2003;45(09):603-612.

12. Rempel G. The importance of good nutrition in children with cerebral palsy. *Phys Med Rehabil Clin N Am.* 2015;26(1):39-56.

13. Aurélio SR, Genaro KF, Macedo Filho ED. Comparative analysis of swallowing patterns between children with cerebral palsy and normal children. *Rev Bras Otorrinolaringol.* 2002;68(2):167-173.

14. Mehta NM, Corkins MR, Lyman B, et al. Defining pediatric malnutrition a paradigm shift toward etiology-related definitions. *JPEN J Parenter Enteral Nutr.* 2013;37(4):460-481.

15. Minihan PM, Fitch SN, Must A. What does the epidemic of childhood obesity mean for children with special health care needs? *J Law Med Ethics.* 2007;35(1):61-77.

16. Sellers D. *Development of a functional eating and drinking ability classification system for individuals with cerebral palsy (*PhD dissertation, University of Brighton); 2014.

17. Sellers D, Mandy A, Pennington L, Hankins M, Morris C. Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Dev Med Child Neurol.* 2014;56(3):245-251.

18. *Stata Statistical Software: Release 14* [computer program]. College Station, TX: StataCorp LP; 2015.

19. Beighley JS, Matson JL, Rieske RD, Adams HL. Food selectivity in children with and without an autism spectrum disorder: Investigation of diagnosis and age. *Res Dev Disabil.* 2013;34(10):3497-3503.

20. Davis JN, Lê K-A, Walker RW, et al. Increased hepatic fat in overweight Hispanic youth influenced by interaction between genetic variation in PNPLA3 and high dietary carbohydrate and sugar consumption. *Am J Clin Nutrn.* 2010;92(6):1522-1527.

21. Stevens J, Ahn K, Houston D, Steffan L, Couper D. Dietary Fiber Intake and Glycemic Index and Incidence of Diabetes in African-American and White Adults The ARIC Study. *Diabetes care.* 2002;25(10):1715-1721.

22. Peterson MD, Ryan JM, Hurvitz EA, Mahmoudi E. Chronic conditions in adults with cerebral palsy. *JAMA.* 2015;314(21):2303-2305.

23. Danaei G, Ding EL, Mozaffarian D, et al. The preventable causes of death in the United States: comparative risk assessment of dietary, lifestyle, and metabolic risk factors. *PLoS Med.* 2009;6(4):e1000058.

24. Cheadle A, Psaty BM, Curry S, et al. Community-level comparisons between the grocery store environment and individual dietary practices. *Prev Med.* 1991;20(2):250-261.

25. Giang T, Karpyn A, Laurison HB, Hillier A, Perry RD. Closing the grocery gap in underserved communities: the creation of the Pennsylvania Fresh Food Financing Initiative. *J Public Health Manag Pract.* 2008;14(3):272-279.

26. Buchholz DW. What is dysphagia? *Dysphagia.* 1996;11(1):23-24.

27. Gisel EG, Applegate-Ferrante T, Benson J, Bosma JF. Oral-motor skills following sensorimotor therapy in two groups of moderately dysphagic children with cerebral palsy: aspiration vs nonaspiration. *Dysphagia.* 1996;11(1):59-71.

Appendix

Table 1. *Social and Physical Characteristics of Children with Cerebral Palsy*

n= 42	
Mean Age (years ± SD)	8.2 ± 5.5
Race/Ethnicity (%)	
Non-Hispanic Black/AA	19 (45.2)
Non-Hispanic White	6 (14.3)
Latino/Hispanic	5 (11.9)
Other	11 (26.2)
Don't know	1 (2.4)
Sex (%)	
Male	21 (50.0)
Female	21 (50.0)
Income (%)	
<$25,000	15 (41.7)
$25,000-49,999	9 (25.0)
$50,000+	3 (8.3)
Don't know/Refused	9 (25.0)
Marital Status (%)	
Single, never married	26 (61.9)
Married	10 (23.8)
Widowed/Divorced/Separated	5 (11.9)
Refused	1 (2.4)
Parental Education (%)	
Less than HS	9 (23.7)
High School	10 (26.3)
Some college, trade school, associates degree	11 (28.9)
> College	8 (21.1)
Employment Status (%)	
Employed for wages	14 (36.8)
Not employed	24 (63.2)
Health Insurance Type (%)	
Medicaid	32 (93.6)
Other	2 (5.6)
Don't know/Refused	2 (5.6)

Physical Characteristics	
EDACS (%)	
Level I (no limitations)	17 (41.5)
Level II	11 (26.8)
Level III	6 (14.6)
Level IV	6 (14.6)
Level V (most limitations)	1 (2.4)
Mean Height (inches ± SD)	46.3 ± 11.6
Mean Weight (lbs. ± SD)	63.0± 42.08
BMI (%)	
Underweight	9 (22.0)
Healthy weight	22 (58.5)
Overweight	3 (7.3)
Obese	5 (12.2)
CP Type (%)	
Hemiplegia	7 (25.0)
Diplegia	7 (25.0)
Monoplegia	5 (17.9)
Quadriplegia	9 (32.1)
Walking Ability	
Ambulatory	23 (56.1)
Non-ambulatory	17 (41.5)
Physically Active (past 7 days) (%)	
Yes	20 (88.0)
No	2 (8.7)
Don't Know	1 (4.4)
Electronics use (%)	
None	9 (24.3)
< 1 hour/day	3 (8.1)
1-3 hours/day	15 (40.5)
≥4 hours/day	10 (27.0)

Table 2. *Mean Observed and Recommended Macronutrients per day in Children with Cerebral Palsy*

n=35	**Ages 2-3 n=10**	**Recommended[1]**	**Ages 4-8 n=8**	**Recommended[1]**	**Ages 9-13 n=9**	**Recommended[1]**	**Ages 14-18 n=8**	**Recommended[1]**
	Mean (SD)		**Mean (SD)**		**Mean (SD)**		**Mean (SD)**	
Total Caloric Intake (kcal[2])	1,120.6 (381.8)	1,000	1,318.6 (296.8)	1,200-1,400	1,767.4 (494.7)	1,400-2,000	1,570.2 (555.4)*	1,800-2,400
Carbohydrates (g[3])	138.6 (42.4)	130	180.5 (66.3)*	130	238.1 (66.8)*	130	218.1 (102.5)*	130
Protein (g)	40.1 (19.9)*	13	66.7 (20.1)*	19	78.8 (33.4)*	34	75.4 (32.8)*	46-52
Dietary Fiber (g)	11.8 (5.1)	14	14.9 (5.8)	16.8-19.6	17.8 (4.4)*	22.4-25.2	13.4 (9.1)*	25.2-30.8
Total Sugar (g)	55.5 (24.6)*	25	69.5 (49.8)*	30-35	80.4 (27.6)*	40-50	68.9 (33.8)	45-60
Total Fat (g)	35.5 (14.2)*	11	50.7 (21.8)*	13-16	72.0 (19.2)*	18-22	59.0 (26.3)*	20-27
Saturated Fat	12.5 (7.5)	-	17.1 (12.6)	-	22.6 (6.2)	-	21.6 (10.4)	-
Cholesterol (mg[4])	70.4 (69.2)	<300	265.5 (151.4)	<300	214.5 (1152.9)	<300	304.5 (161.6)	<300

*Denotes significant differences between age groups (p<0.05)
[1]2015 Dietary Guidelines for Americans 8th Edition, U.S. Department of Health and Human Services and U.S. Department of Agriculture
[2]kilocalories
[3]grams
[4]milligrams
Note: FoodWorks software was used to calculate macronutrient

Table 3. *Mean Observed and Recommended Minerals per day in Children with Cerebral Palsy*

n=35	**Ages 2-3 n=10**	**Recommended[1]**	**Ages 4-8 n=8**	**Recommended[1]**	**Ages 9-13 n=9**	**Recommended[1]**	**Ages 14-18 n=8**	**Recommended[1]**
	Mean (SD)		**Mean (SD)**		**Mean (SD)**		**Mean (SD)**	
Iron (mg[2])	11.2 (6.8)*	7	14.7 (5.1)*	10	16.0 (6.3)*	8	13.3 (6.7)	11-15
Phosphorus (mg)	734.9 (328.6)*	460	985.6 (212.0)*	500	1,324.3 (295.3)	1,250	1,239.6 (593.5)	1,250
Potassium (mg)	1,249.2 (546.4)*	3,000	2,024.6 (558.9)*	3,800	2,551.2 (533.6)*	4,500	2,686.3 (1531.8)*	4,700
Zinc (mg)	5.3 (2.1)*	3	8.3 (3.2)*	5	13.0 (6.1)*	8	8.8 (4.7)	9-11
Sodium (mg)	1,376.2 (939.5)	1,500	2,108.2 (920.7)	1,900	3,217.1 (1455.2)*	2,200	2,839.2 (1194.6)	2,300
Calcium (mg)	583.5 (507.8)	700	608.0 (304.7)*	1,000	805.0 (348.1)*	1,300	883.6 (569.5)*	1,300
Magnesium (mg)	163.1 (40.6)*	80	193.4 (37.5)*	130	257.9 (66.8)	240	235.7 (107.0)	360-410

*Denotes significant differences between age groups ($p<0.05$)

[1]2015 Dietary Guidelines for Americans 8th Edition, U.S. Department of Health and Human Services and U.S. Department of Agriculture

[2]milligram [3]microgram

Note: FoodWorks was used to calculate minerals

Table 4. *Mean Observed and Recommended Vitamins per day in Children with Cerebral Palsy*

n=35	**Ages 2-3 n=10**	**Recommended[1]**	**Ages 4-8 n=8**	**Recommended[1]**	**Ages 9-13 n=9**	**Recommended[1]**	**Ages 14-18 n=8**	**Recommended[1]**
	Mean (SD)		**Mean (SD)**		**Mean (SD)**		**Mean (SD)**	
Vitamin A (mg RAE)	223.1 (236.3)	300	528.0 (683.5)	400	345.7 (404.7)*	600	912.5 (1507.3)	700-900
Vitamin C (mg)	31.7 (30.7)	15	83.3 (57.1)*	25	68.6 (55.3)	45	136.6 (180.1)	65-75
Vitamin E (mgAT[4])	4.1 (3.1)	6	5.4 (3.4)	7	8.2 (3.2)	11	4.7 (2.3)	15
Vitamin B_6 (mg)	1.3 (0.68)*	0.5	2.2 (1.0)*	0.6	2.7 (1.4)*	1	2.3 (1.7)	1.2-1.3
Vitamin B_{12} (mcg[3])	2.4 (2.4)*	0.9	4.1 (2.5)*	1.2	4.7 (1.4)*	1.8	5.4 (3.0)*	2.4
Vitamin D (mcg)	1.4 (2.7)*	15	2.5 (3.4)*	15	3.1 (3.3)*	15	1.8 (2.01)*	15
Vitamin K (mcg)	38.6 (50.5)	30	117.9 (142.5)	55	77.3 (69.8)	60	60.1 (45.3)	75
Thiamin (mg)	1.2 (0.6)*	0.5	1.5 (0.4)*	0.6	2.1 (0.9)*	0.9	1.8 (1.1)*	1-1.2
Riboflavin (mg)	1.3 (0.8)*	0.5	1.6 (0.6)*	0.6	2.2 (1.0)*	0.9	2.2 (1.4)*	1-1.3
Folate (mg DFE[4])	211.5 (90.7)*	150	334.3 (102.2)*	200	377.2 (160.3)	300	342.2 (148.5)	400

*Denotes significant differences between age groups ($p<0.05$)

[1]2015 Dietary Guidelines for Americans 8th Edition, U.S. Department of Health and Human Services and U.S. Department of Agriculture [2]milligram [3]microgram [4]Dietary folate equivalent

Note: FoodWorks was used to calculate vitamins

Table 5. *Frequency of Food Intake in Children with Cerebral Palsy from NHNAES FFQ*

n=42	Seldom n (%)	Sometimes n (%)	Often n (%)	Very Often n (%)
Vegetables	4 (9.5)	32 (76.2)	4 (9.5)	2 (4.8)
Fruits	0	10 (23.8)	25 (59.5)	7 (16.7)
Meats	14 (33.3)	22 (52.4)	1 (2.4)	5 (11.9)
Fats	11 (26.2)	22 (52.4)	5 (11.9)	4 (9.5)
Grains	7 (16.7)	18 (42.9)	14 (33.3)	3 (7.1)
Nuts/Legumes	18 (42.9)	12 (28.6)	9 (21.4)	3 (7.1)
Sugars	12 (28.6)	20 (47.6)	7 (16.7)	3 (7.1)
Dairy	7 (21.4)	12 (35.7)	12 (31.0)	6 (11.9)
	Seldom n (%)	**Often n (%)**	**Very Often n (%)**	
Milk	31 (73.8)	4 (9.5)	7 (16.7)	
Juice	20 (47.6)	16 (38.1)	6 (14.3)	

Figure 1. *Eating and Drinking Ability Classification System Description*

Level	EDACS
Level I	Eats and drinks safely and efficiently
Level II	Eats and drinks safely but with some limitations to efficiency
Level III	Eats and drinks with some limitations to safety; there may be some limitations to efficiency
Level IV	Eats and drinks with significant limitations to safety
Level V	Unable to eat or drink safely- tube feeding may be considered to provide nutrition

Figure 2. *Developing Quartiles and Tertiles of Food Groups by Raw Score*

	Seldom	Sometimes	Often	Very Often
Vegetables	0-24	25-48	49-72	73-96
Fruits	0-19	20-38	39-57	58-76
Meats	0-29	30-58	59-87	88-116
Fats	0-14	15-28	29-42	43-56
Grains	0-17	18-34	35-51	52-68
Nuts/Legumes	0-4	5-8	9-12	13-16
Sugars	0-15	16-30	31-45	46-60
Dairy	0-4	5-8	9-12	13-16
Milk	0-3		4-6	7-9
Juice	0-6		7-12	13-18

Bivariate Associations between Overweight/Obesity and Dietary Intake in Children with Cerebral Palsy: A Matched Case Control Study

Abstract

Background/Purpose: Obesity is an emerging problem for children with special needs including children with CP. Prevalence rates of studies have established between 16-29% of children with CP are overweight or obese. Unlike typically developed children, children with CP display various feeding abilities, which may influence their nutritional status. Most studies examining overweight/obesity in children with CP have focused on prevalence rates or feeding method. Therefore the purpose of this study was to determine whether dietary intake is associated with overweight and obesity among children with CP.

Methods: Descriptive analysis was performed on the entire sample (n=84), stratified by feeding method. χ^2 tests conducted to assess differences between groups. We performed a matched case-control analysis, with 14 overweight or obese patients matched to 14 underweight and normal patients from the data set of 84 patients. Patients were matched 1:1 by age (± 2 years) and placement of GT. Exact McNemar's χ^2 tests and t-tests were performed to assess associations in demographics and food intake between cases and controls.

Results: Analysis on all 84 participants found significant differences in race, EDACS level, walking ability, and electronics use by feeding method. There were differences in race and health insurance status between cases and controls. Total caloric intake was similar while cases and controls showed significant differences in vegetable intake. No other differences between cases and control in relation to all other food groups.

Conclusions: Few differences between cases and controls and the small percentage of overweight/obesity in the study suggest that increased body weight is not a prevalent issue among our sample. However these findings may be a result of best practices implemented unique to the clinic such as the presence of a clinical registered dietitian and early intervention and counseling for children that display inadequate nutritional status. Future research should employ longitudinal methods to study overweight/obesity among children with CP in various settings.

Introduction

Cerebral palsy is the most common cause of physical disability in children. CP is a permanent group of non-progressive neurological disorders often affecting body movement, coordination and posture, and is usually diagnosed in early infancy or childhood.[1] And estimated 1 in 323 (3.1 per 1,000) children in the United States have been diagnosed with CP.[2] This wide-ranging disorder may often occur along with intellectual, visual, hearing, cognitive, and behavioral impairments.[3]

Obesity is an emerging problem for children with typical development and children and youth with special health care needs (CYSHCN), including children with CP. Twenty-two percent of CYSHCN are obese, making rates in CYSHCN greater than typically developed children in the US.[4] Obesity in CYSHCN leads to a number of secondary conditions similar to all populations, such as asthma, sleep apnea, orthopedic complications, non-alcoholic fatty liver, and type II diabetes.[5,6] These concurrent health conditions may carry an additional burden on the already diminished social, physical, and mental health of CYSHCN.[5] However, there is a paucity of research establishing trends in obesity in CYSHCN, especially children with CP in the United States.

Several studies have determined prevalence rates in smaller samples of children with CP in clinical settings. Estimated rates of overweight and obesity from a longitudinal study of children with CP progressively increased from 7%-16% within a decade.[7] This study also reported patients with mild-moderate gross motor function impairment and hemiplegic CP experienced a significant increase in obesity across the ten-year period.[7] Hurvitz and colleagues (2008) found approximately 29.1% of children

with CP had a BMI above the normal range.[8] Similarly, Sison-Williamson et al. (2014) reported 36% of their sample being overweight and obesity.[9]

At present, life expectancy for well-functioning individuals with CP is close to that of the general population. As these survival rates increase, the risk of developing chronic diseases also increases.[10] For example data from Peterson et al. (2013) shows adults with CP have a two to threefold increase in the risk of coronary heart disease mortality when compared to the general population. This higher risk may be due to motor impairment and sedentary behavior that are characteristic of individuals with CP. Moreover patients of CP are becoming increasingly at risk for muscle dysfunction and obesity-related cardiometabolic disease.[11] A study conducted by van der Slot and colleagues (2013) found many risk factors of CVD present in a sample of young adults with CP. Furthermore, higher body fat was associated with an increased 10-year risk of developing CVD.[10]

Nutrition is a major determinant weight status among all children. Although CP primarily affects neurodevelopment, difficulties in growth and nutrition are also common. Common nutrition related challenges among children with CP include underweight, overweight and obesity, and short stature.[12,13] Low intake fruits and vegetables and high intake of fats were found among a Brazilian cohort of children with CP.[14] However due to a lack in surveillance infrastructure in the US for CP a study in the United States attempting to determine the nutritional status of children with CP has yet to be conducted.

Unlike most typically developed children, children with CP may obtain their nutrients through a gastrostomy tube (GT) if they are unable to effectively eat or drink through their mouth. Feeding methods are an important determinant in the growth

outcomes of children with CP. Hurvitz and colleagues (2008) found 28% of their non-ambulatory participants were fed using GT while Østensjø and co-authors (2003) found that 51% of study participants used an assistive device while eating.[8,15] Feeding method (i.e.- GT or oral feeding) has been associated with body weight in children with CP. However studies have found conflicting results. Rogers (2004) found mean weigh to height ratio significantly greater in children with GTs. Furthermore, children with CP experiencing growth failure are often recommended GT feeding.[16] However overfeeding can be an adverse consequence especially among non-ambulant children who have low energy expenditure and are more at risk for overfeeding when compared to ambulant children with CP.[17] In contrast, Hurvitz and colleagues (2008) also found that the presence of a GT had no influence on the prevalence of overweight and obesity.[8]

Given the various abilities in feeding among children with CP, most studies examining overweight and obesity in this population have focused on prevalence rates or feeding methods. Few studies have assessed the potential role dietary intake plays in the overweight/obesity status in this population. Therefore, the purpose of this study was to determine whether the dietary intake is associated with overweight and obesity among children with CP. We hypothesized overweight and obese children in our sample will have less frequent consumption of healthy foods (fruits, vegetables, grains, legumes, dairy and milk) and increased consumption of unhealthy foods (fats, meats, sugars, and juice).

Methods

This analysis comes from a larger study examining the nutritional status of 84 children with CP. We stratified descriptive results by feeding method (GT and oral

feeding/both). To perform a matched case-control analysis, 14 overweight or obese patients were matched to 14 underweight and normal patients from the data set of 84 patients. Patients were matched 1:1 by age (± 2 years) and placement of gastrostomy tube (GT).

For this overall study, we collected cross-sectional parent-reported surveys of dietary intake in children with CP. Surveys administered to parents or legal guardians by the investigator included: demographics survey, NHANES food frequency questionnaire, Eating and Drinking Ability Classification System (EDACS) form, and 24-hour dietary recall. Parents or legal guardians of children ages 2-18 years old were recruited from the Center for Children and Youth with Special Health Care Needs (CYSHCN) at St. Christopher's Hospital for Children in a mid-sized urban children's hospital located in Northern Philadelphia, Pennsylvania. Patients were identified for eligibility in the study by a CP diagnosis found through electronic medical records. Parents or caregivers were then approached for study enrollment during their child's clinic visit at the Center for CYSHCN and written consent was subsequently obtained if they decided to participate in the study. Parents completed the self-reported questionnaires in the exam room while they were waiting for the physician. Families were given a $15 gift to a retail store as compensation for participating in the study. This study was approved by Drexel University's St. Christopher's Hospital for Children Institutional Review Board. Eighteen percent of parents refused to participate or were ineligible for the study due to language barriers.

Measures

Demographic Survey. Parents reported on their child and family socio-demographic characteristics (i.e. age, sex, household income, parental education, household size, health insurance). Parents also reported on other characteristics relating to the child's CP diagnosis (CP type, physical activity ability, and sedentary behavior).

CP type refers to whether the child was hemiplegic, diplegic, monoplegic, or quadriplegic. Parents were questioned about their child's ability to participate in a physical activity and the length of time their child participated in screen time (i.e. television, computers, smart phones, iPads,) to assess sedentary behavior.

EDACS. The EDACS is a newly developed classification instrument that is used to evaluate eating and drinking abilities in children with CP. In the EDACS, eating and drinking performance is measured using five distinct levels, ranging from Level I being no limitations to safety and efficiency to Level V being the most significant limitation to safety and efficiency. The EDACS was found to be a valid and reliable system for measuring eating and drinking functioning among individuals with CP in both clinical and research settings.[18,19]

NHANES Food Frequency Questionnaire (FFQ). The NHANES food frequency questionnaire was administered to parents in order to gain a comprehensive assessment of the child's frequency of dietary intake over the past 12 months, (FFQ). Some children with CP receive their nutrients through a gastrostomy tube if they have dysphagia and/or difficulty with chewing and swallowing solid foods and in many cases, they consequently consume liquid nutritional supplements (i.e.: toddler or adult formulas) through the gastrostomy tube. Therefore since children with a GT solely consume formula, an FFQ was only administered for children who consumed food by mouth.

Each item in the FFQ reported the child's frequency of consuming foods on a daily, weekly, monthly, or yearly basis. The respondent can choose from a total of 11 answer choices that ranged from 'Never' to '2 or more times per day.' Items in the FFQ were combined according to the following food groups: vegetables, fruits, meats, grains, nuts/legumes, sugars, milk, and juice. While solid foods in the FFQ were reported on a daily, weekly, monthly, and yearly basis, consumption of beverages were reported on a daily, weekly, and monthly basis only.

24-Hour Dietary Recall. The 24-hour dietary recall was used in this analysis to calculate total caloric intake in children in our sample.

Walking Ability. Walking ability as an indicator of the child's motor functioning ability was measured through the following question in the demographic survey that inquired about the child's physical ability to participate in physical activity: *"Does your child's (medical, behavioral, or other health conditions / emotional, developmental, or behavioral problems) interfere with [his/her] ability to participate in sports, clubs, organized activities, or play with other children?"*

Data Analysis

Descriptive statistics were performed to establish individual and demographic characteristics of the 84 patients in our study. Chi-square (χ^2) tests were run to assess differences in individual and demographic characteristics by feeding method.

Scoring the NHANES FFQ involved summing items within each food groups (vegetables, fruits, meats, grains, nuts/legumes, sugars, milk, and juice) to calculate intake frequencies. A higher score indicated increased consumption of the food group. The scores for the aforementioned food groups were then divided into quartiles based on

the following Likert scale: seldom, sometimes, often, and very often. Since beverages were reported on daily, weekly, and monthly basis, we divided these scores into tertiles. Frequency score for tertiles were based on the following Likert scale: seldom, sometimes, and often.

Matched Case Control Analysis

Differences between the cases and controls were evaluated using paired t-test for continuous variables and the exact McNemar's chi-square test for categorical variables. In order to conduct the McNemar's chi-square test, all predictor variables were dichotomized. An exact McNemar's chi-square test was used to take into account the small sample size in our analysis. Since the NHANES FFQ was administered to patients who were only orally fed, the sample size for analyses looking at the differences between the matched groups in relation to frequency of food intake was restricted to 8 cases and 8 controls. Due to some missing data (i.e.-income, race, health insurance type etc.) analyses looking at matched groups in relation to demographic characteristics did not equal n=14 per group. All statistical analyses were conducted using SAS software (Version 9.4, SAS Institute).

Results

Characteristics of 84 Patients Stratified by Feeding Method

Individual and demographic characteristics are presented in Table 1. There were 39 participants (46%) that consumed nutrients through a GT and 45 participants (54%) that consumed nutrients through mouth or both means. The mean age of participants was similar among feeding method; 8.8 ± 5.1 years among children using a GT and 8.3 ± 5.4 years among children who were orally fed or used both feeding methods. Total caloric

intake among children using GT was 1,266.1 ± 3,410 kilocalories (kcals) and 1,429.3 ± 487.1 kcals among oral or both feeding methods. The ethnic composition among all participants in our sample was predominantly Black, lower income (<$25,000 annually), not employed, and enrolled in Medicaid. The majority of children were within a healthy BMI.

While the aforementioned descriptive results were similar among the two groups, noticeable differences between groups were also noted. The majority of parents with children using a GT had a high school education(40%) while most parents with orally fed children had some college, trade school, or associate's degree. Furthermore, 45% of children eating through a GT were diplegic compared to 31% of children who ate foods through mouth had quadriplegia. Ninety-two percent of GT fed children had were identified as EDACS Level V while the distribution of eating and drink ability was more varied in children who ate through mouth and GT. Although the majority of both GT fed and orally fed children were non-ambulatory (80% and 57%, respectively), a higher percentage of children that were either orally fed or used both feeding methods were ambulatory compared to children that only ate through a GT. Finally a greater proportion of children that either orally fed or used both feeding methods utilized electronics more than GT fed children.

Matched Case-Control Analysis

Characteristics of 28 Matched Patients

Demographic and individual characteristics of matched patients with cerebral palsy are presented in Table 2. The mean age of our controls was 6.9 years ± 4.4 while mean age among cases was 7.0 ± 4.5. Groups were similar in regards to sex, marital

status, walkability, and electronic use. There were significant differences in race; with a higher proportion of Black and Latino patients than White patient in our sample. Health insurance was also significantly different; with the majority of patients having Medicaid compared to any other form of health insurance. There were moderate differences parental education and employment status. Ninety-two percent of controls had a high school diploma or greater compared to 7% with less than a HS education. In contrast, among cases 62% of participants had high school degree or greater while 39% had less than a high school education. A greater distribution of both cases and controls were not employed. Among controls, there were approximately 43% of patients had mild-moderate eating and drinking impairment (EDACS I-III) compared to 57% with severe eating and drinking impairment (EDACS IV-V). Among cases, 29% of children had mild-moderate eating and drinking ability (EDACS I-III) compared to 71% with severe eating and drinking ability (EDACS IV-V). Finally, a greater proportion of cases (79%) were ambulatory when compared to controls.

Food Intake in 28 Matched Patients

Food intake among our matched patients with cerebral palsy is presented in Table 3. The mean total caloric intake among controls was 1,345.6 ± 541.3 kcals compared to 1,359.8 ± 512.5 kcals among cases. Significant differences in vegetable consumption were reported; 100% of controls and 75% of cases reported seldom eating vegetables. While there were no differences between groups in relations to sugar, legumes/nuts, milk, and juice consumption, trends found in the consumption of all food groups are important to note. Both cases and controls displayed equal intake of meats, with low consumption of meats among both groups. A greater percentage of controls consume dairy frequently

compared to cases. Cases and control seldom ate fats and grains while frequently eating fruits. However among cases, consumption of grains was less frequent compared to controls.

Discussion

In this study, we hypothesized that overweight and obese children with CP will have an unbalanced food intake compared to underweight and normal weight children. However when assessing dietary intake in relation to overweight and obesity, we found no differences in the nutritional status of overweight and obese children with CP compared to underweight and normal weight children with CP. While other studies have found elevated rates of overweight and obesity among children with CP,[7-9] our overall sample of children with CP had substantially fewer children over a normal BMI percentile, suggesting that among our sample overweight/obesity is not a prevalent issue.

Our results revealed that mean total caloric intake among overweight/obese children with CP was similar to total caloric intake among underweight/normal weight children with CP. This may be a results of best practices implemented at the Center for CYSHCN, when a patient exhibits signs of inadequate nutritional status (i.e.- underweight or overweight/obese) they are immediately referred to the clinic's registered dietitian (RD). If the child presents nutritional deficiencies, the physician will consult the RD, who subsequently alters the child's intake of either foods and/or formula. If a child is overweight or obese, the RD will adjust caloric needs based on the patient's current body weight and ideal body weight. [(current body weight – ideal body weight x 0.25)] + ideal body weight] Therefore similar total caloric intake between cases and controls as well as the equal frequencies in the consumption of major foods groups may be due to

overweight/obese children already receiving nutritional counseling to adjust their total caloric intake. Many children with CP tend to be smaller and have poor nutrition, with up to 50% undernourishment among children with CP.[20,21] The equal proportions of underweight and overweight/obese children in our total sample may further exemplify positive changes to diet due to early nutritional intervention by the clinical dietitian at the Center for CYSHCN.

While this procedure for monitoring inadequacies in nutritional status is commonplace at the Center for CYSHCN, this may not be conventional practice at other clinics. Most primary care clinics lack dietitians that are part of the team of health care providers. Thorensen et al. (2008) found that approximately 70% of doctors and nurses indicated that a clinical dietitian rarely visited their clinic. Furthermore, doctors and nurses were inclined to prioritize nutrition among their patients when there was a greater access to a clinical dietitian in their clinics and found it less difficult to diagnose nutritional problems in their patients.[22]

Numerous studies have used NHANES food frequency data to establish nutritional status among all children in the United States.[23-25] Typically developed obese children consume less dairy, total grains, fruits and vegetables and more energy dense, nutrient-poor foods.[23,24] Similarly in our matched sample, overweight/obese cases consumed less dairy and grains compared to their underweight and normal weight counterparts. Although there were few differences in food intake among cases and controls, some cases in our sample may not be consuming adequate amounts of healthy foods. Furthermore, while our results revealed that normal weight and overweight/obesity children with CP have similar food intake, it is also important to note that this trend may

not be typical of other children with CP, especially from low-income families who do not have access to resources similar to patients at the Center for CYSHCN.

While very few studies have attempted to examine the nutritional status among children with CP, there is emerging literature describing nutritional status and dietary intake in this population.[14,26,27] However none of these studies have been conducted in populations within the United States. To our knowledge this is the first United States based study to explore the impact of food intake on overweight and obesity among children with cerebral palsy. Various co-occurring conditions exist among children with CP, which may subsequently lead to varying degrees of eating abilities among this population. Since eating abilities may impact weight status in children with CP,[17] our study attempted to capture these various abilities by enrolling both children that feed through a GT and children that orally feed.

Despite these strengths, there are several limitations to this study. We were unable to establish parent-reported Gross Motor Functioning Classification System (GMFCS) levels in our sample due to a high percentage of missing data. Instead we measured walking ability (ambulatory vs. non-ambulatory children) through a physical activity question in our demographic survey. When assessing food intake among our matched patients, we had to exclude children who only consumed formula, further limiting our sample. Our study was restricted by a very small sample size, which may have affected our ability to detect significant differences between our matched groups. However due to the lack of previous research in the United States, this study was nevertheless able to establish trends in the impact of food intake on overweight and obesity in children with CP, which may serve as precedent for future studies utilizing primary data collection.

Selection bias may have also occurred since our sample was restricted to parents who were able to speak English therefore excluding many parents who communicated in Spanish. Lastly, our study is limited to children with similar ethnic, socioeconomic, geographic, and clinic characteristics. Therefore our study may be less generalizable to other populations. Future research should longitudinally assess food intake and body weight in children with CP, as it is difficult to infer causality in cross-sectional studies.

Conclusion

Our overall results suggests that food intake among children with CP is not associated with overweight and obesity. Due to limitations such as a small sample size and commonplace nutritional interventions at the patient's clinic, these findings may not be generalizable to other populations however this is of the first studies to examine what children are eating and how it may affect weight. Therefore further research conducted in different populations to assess the impact of food intake among children with CP and its relation to overweight/obesity using longitudinal methods is essential. Clinical implications of this study suggest that this research may raise awareness of nutrition among children with CP in both parents and clinicians. These findings also demonstrates the importance of having a clinical dietitian as part of the health care team to reduce nutrition and weight related issues in children with special health care needs. As the presence of clinical dietitians are not typical of all pediatric clinics, including a clinical dietitian as part of the comprehensive team of providers that care for the patient with CP may lead to healthy weight and a well-balanced diet.

References

1. National Institute of Health [NIH]. Cerebral Palsy: Hope Through Research. 2013; http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm. Accessed June 1, 2016.

2. Christensen D, Van Naarden Braun K, Doernberg NS, et al. Prevalence of cerebral palsy, co□occurring autism spectrum disorders, and motor functioning–Autism and Developmental Disabilities Monitoring Network, USA, 2008. *Dev Med Child Neuro.* 2014;56(1):59-65.

3. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl.* 2007;109(109):8-14.

4. Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of childhood and adult obesity in the United States, 2011-2012. *JAMA.* 2014;311(8):806-814.

5. Rimmer JH, Rowland JL, Yamaki K. Obesity and secondary conditions in adolescents with disabilities: Addressing the needs of an underserved population. *J Adolesc Health.* 2007;41(3):224-229.

6. Grondhuis S, Aman M. Overweight and obesity in youth with developmental disabilities: a call to action. *J Intellect Disabil Res.* 2014;58(9):787-799.

7. Rogozinski BM, Davids JR, Davis RB, et al. Prevalence of obesity in ambulatory children with cerebral palsy. *J Bone Joint Surg Am.* 2007;89(11):2421-2426.

8. Hurvitz EA, Green LB, Hornyak JE, Khurana SR, Koch LG. Body mass index measures in children with cerebral palsy related to gross motor function classification: a clinic-based study. *Am J Phys Med Rehabil.* 2008;87(5):395-403.

9. Sison-Williamson M, Bagley A, Gorton G, Johnson BA, Oeffinger D. Analysis of the relationships that body composition and muscular strength have with oxygen cost of walking in children with cerebral palsy. *Gait Posture.* 2014;40(4):628-632.

10. van der Slot W, Roebroeck ME, Nieuwenhuijsen C, et al. Cardiovascular disease risk in adults with spastic bilateral cerebral palsy. *J Rehabil Med.* 2013;45(9):866-872.

11. Peterson M, Gordon P, Hurvitz E. Chronic disease risk among adults with cerebral palsy: the role of premature sarcopoenia, obesity and sedentary behaviour. *Obes Rev.* 2013;14(2):171-182.

12. Ekvall VK. *Pediatric nutrition in chronic diseases and developmental disorders: prevention, assessment, and treatment.* Oxford University Press; 2005.

13. Yang Y, Lucas B, Feucht S. *Nutrition Interventions for Children with Special Health Care Needs.* Washington State Department of Health; 2010.

14. Lopes PAC, Amancio OMS, Araújo RFC, Vitalle MSdS, Braga JAP. Food pattern and nutritional status of children with cerebral palsy. *Rev Paul Pediatr.* 2013;31(3):344-349.

15. Østensjø S, Carlberg EB, Vøllestad NK. Everyday functioning in young children with cerebral palsy: functional skills, caregiver assistance, and modifications of the environment. *Dev Med Child Neurol.* 2003;45(09):603-612.

16. Rogers B. Feeding method and health outcomes of children with cerebral palsy. *J Pediatr.* 2004;145(2):S28-S32.

17. Sullivan P. Nutrition and growth in children with cerebral palsy: setting the scene. *Eur J Clin Nutr.* 2013;67:S3-S4.

18. Sellers D. *Development of a functional eating and drinking ability classification system for individuals with cerebral palsy*, (PhD dissertation, University of Brighton); 2014.

19. Sellers D, Mandy A, Pennington L, Hankins M, Morris C. Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Dev Med Child Neurol.* 2014;56(3):245-251.

20. Rempel G. The importance of good nutrition in children with cerebral palsy *Phys Med Rehabil Clin N Am.*. 2015;26(1):39-56.

21. Petersen MC, Kedia S, Davis P, Newman L, Temple C. Eating and feeding are not the same: caregivers' perceptions of gastrostomy feeding for children with cerebral palsy. *Dev Med Child Neurol.* 2006;48(09):713-717.

22. Thoresen L, Rothenberg E, Beck AM, Irtun Ø. Doctors and nurses on wards with greater access to clinical dietitians have better focus on clinical nutrition. *J Hum Nutr Diet.* 2008;21(3):239-247.

23. Cribb V, Emmett P, Northstone K. Dietary patterns throughout childhood and associations with nutrient intakes. *Public Health Nutr.* 2013;16(10):1801-1809.

24. Keast DR, Fulgoni VL, Nicklas TA, O'Neil CE. Food sources of energy and nutrients among children in the United States: National Health and Nutrition Examination Survey 2003–2006. *Nutrients.* 2013;5(1):283-301.

25. Bradlee ML, Singer MR, Qureshi MM, Moore LL. Food group intake and central obesity among children and adolescents in the Third National Health and Nutrition Examination Survey (NHANES III). *Public health Nutr.* 2010;13(06):797-805.

26. Benfer KA, Weir KA, Bell KL, Ware RS, Davies PS, Boyd RN. Longitudinal cohort protocol study of oropharyngeal dysphagia: relationships to gross motor attainment, growth and nutritional status in preschool children with cerebral palsy. *BMJ Open.* 2012;2(4):e001460.

27. Dahlseng MO, Finbråten AK, Júlíusson PB, Skranes J, Andersen G, Vik T. Feeding problems, growth and nutritional status in children with cerebral palsy. *Acta Paediatr.* 2012;101(1):92-98.

Appendix

Table 1. *Individual and Demographic Characteristics of Children with Cerebral Palsy, Stratified by Feeding Method*

	Only Gastrostomy Tube n=39	**Orally or Both** n=45	***p-value***
Mean age (years ± SD)	8.8 ± 5.1	8.3 ± 5.4	0.338
Age (%)			0.484
2-3 years	10 (26.6)	12 (26.7)	
4-8 years	7 (18.0)	13 (28.9)	
9-13 years	14 (35.9)	10 (22.2)	
14-18 years	8 (20.5)	10 (22.2)	
Total Caloric Intake (kcal)	1,266.1 ± 3410	1,429.3 ± 487.1	0.958
Race/Ethnicity (%)			0.039*
Non-Hispanic Black/AA	17 (44.5)	21 (46.7)	
Non-Hispanic White	3 (7.7)	6 (13.3)	
Latino/Hispanic	15 (38.5)	7 (15.6)	
Other	3 (7.7)	11 (24.5)	
Sex (%)			0.260
Female	16 (41.0)	24 (53.3)	
Male	23 (59.0)	21 (46.7)	
Income (%)			0.667
<$25,000	13 (37.1)	17 (43.6)	
$25,000-49,999	11 (31.4)	10 (25.6)	
$50,000+	4 (11.4)	2 (5.1)	
Don't know/Refused	7 (20.0)	10 (25.6)	
Marital Status (%)			0.066
Single, never married	15 (39.5)	29 (64.4)	
Married	13 (34.2)	10 (22.2)	
Widowed/Divorced/ Separated	9 (23.7)	5 (11.1)	
Parental Education (%)			0.451
Less than HS	9 (23.7)	9 (22.0)	
High School	15 (39.5)	11 (26.8)	
Some college, trade school, associate degree	8 (21.1)	15 (36.6)	
≥College	6 (15.8)	6 (14.6)	
Employment Status (%)			0.262
Employed for wages	10 (27.0)	16 (39.0)	
Not employed	27 (73.0)	25 (61.0)	

Health Insurance Type (%)			0.828
Medicaid	28 (84.9)	35 (89.8)	
Other	2 (6.06)	2 (2.6)	
Physical Characteristics			
CP Type (%)			0.163
Hemiplegia	3 (10.3)	9 (28.1)	
Diplegia	13 (44.8)	7 (21.9)	
Monoplegia	4 (13.8)	6 (18.8)	
Quadriplegia	9 (31.0)	10 (31.3)	
EDACS (%)			<0.0001*
Level I	-	17 (38.6)	
Level II	-	11 (25.0)	
Level III	-	6 (13.6)	
Level IV	3 (7.9)	9 (20.5)	
Level V	35 (92.1)	1 (2.3)	
Mean Height (inches ± SD)	45.1 ± 9.9	46.4 ± 11.5	0.699
Mean Weight (lbs. ± SD)	56.6 ± 24.9	62.3 ± 41.9	0.772
BMI (%)			0.824
Underweight	5 (14.7)	9 (20.5)	
Healthy weight	22 (64.7)	28 (63.6)	
Overweight	3 (8.8)	2 (4.6)	
Obese	4 (11.8)	5 (11.4)	
Walking Ability (%)			0.002*
Ambulatory	8 (20.5)	18 (40.9)	
Non-ambulatory	31 (79.5)	25 (56.9)	
Don't Know	-	1 (2.3)	
Physical Activity (%)			0.773
Yes	6 (85.7)	22 (88.0)	
No	1 (14.3)	2 (8.8)	
Electronics use (%)			
None	18 (50.0)	7 (18.0)	0.013*
< 1 hour/day	-	3 (7.7)	
1-3 hours/day	10 (27.8)	19 (48.7)	
≥4 hours/day	8 (22.2)	10 (25.6)	

*$p<0.05$

Table 2. *Individual and Demographic Characteristics of Cases and Controls with Cerebral Palsy*

	Controls (Underweight/Normal) n=14	**Cases** (Overweight/Obese) n=14	*p-value*
Age (years ± SD)	*Matched* 6.9 ± 4.4	*Matched* 7.0 ± 4.5	-
Race/Ethnicity (%)			0.0352*
Non-Hispanic White	2 (14.3)	3 (23.1)	
Black/Latino/Other	12 (85.7)	10 (76.2)	
Sex (%)			0.7744
Female	7 (50.0)	5 (35.7)	
Male	7 (50.0)	9 (64.3)	
Income (%)			0.7266
<$25,000	5 (62.5)	5 (50.0)	
≥ $25,000	3 (37.5)	5 (50.0)	
Marital Status (%)			0.7539
Single, never married	7 (53.9)	4 (28.6)	
Married/Widowed/ Divorced/Separated	6 (46.2)	10 (71.4)	
Parental Education (%)			0.0963
Less than HS	1 (7.1)	5 (38.5)	
High School and greater	13 (92.9)	8 (61.5)	
Employment Status (%)			0.1094
Employed for wages	5 (38.5)	2 (15.4)	
Not employed	8 (61.5)	11 (84.6)	
EDACS (%)			0.3877
Level I-III	6 (42.9)	4 (28.6)	
Level IV-V	8 (57.1)	10 (71.4)	
Gastrostomy Tube Placement	*Matched*	*Matched*	-
GT/Both	6 (42.9)	6 (42.9)	
Orally fed	8 (57.1)	8 (57.1)	
Health Insurance Type (%)			0.0020*
Medicaid	10 (100.0)	10 (90.9)	
Other	0	1 (9.1)	
Walking Ability (%)			0.6476
Ambulatory	6 (42.9)	11 (78.6)	
Non-ambulatory	8 (57.1)	3 (21.4)	
Electronics use (%)			0.3018
Does not use	3 (23.1)	5 (38.5)	
Uses	10 (76.9)	8 (61.5)	

*$p<0.05$

Table 3. *Food Intake Among Cases and Controls with Cerebral Palsy*

	Controls (Underweight/Normal) n=8	**Cases** (Overweight/Obese) n=8	*p-value*
Total Caloric Intake (kcal ± SD)	1,345.6 ± 541.3	1,359.8 ± 512.5	<0.001
Fruits (%)			0.3437
Seldom	1 (12.5)	3 (37.5)	
Frequent	7 (87.5)	5 (62.5)	
Grains (%)			0.7266
Seldom	4 (50.0)	6 (85.7)	
Frequent	4 (50.0)	1 (14.3)	
Vegetables (%)			0.0313*
Seldom	8 (100.0)	6 (75.0)	
Frequent	0	2 (25.0)	
Meats (%)			0.0703
Seldom	7 (87.5)	7 (87.5)	
Frequent	1 (12.5)	1 (12.5)	
Fats (%)			0.1797
Seldom	6 (75.0)	7 (87.5)	
Frequent	2 (25.0)	1 (12.5)	
Sugars (%)			0.2891
Seldom	6 (75.0)	6 (75.0)	
Frequent	2 (25.0)	2 (25.0)	
Legumes/Nuts (%)			0.2891
Seldom	6 (75.0)	6 (75.0)	
Frequent	2 (25.0)	2 (25.0)	
Dairy (%)			0.7744
Seldom	3 (37.5)	7 (87.5)	
Frequent	5 (62.5)	1 (12.5)	
Milk (%)			1.000
Seldom	4 (50.0)	4 (50.0)	
Frequent	4 (50.0)	4 (50.0)	
Juice (%)			1.000
Seldom	4 (50.0)	4 (50.0)	
Frequent	4 (50.0)	4(50.0)	

*$p<0.05$

Vita

Purni Mandrika Abeysekara was born on June 8th 1984 in Colombo, Sri Lanka. She moved to Guam with her parents at the age of five before settling in Charlotte, North Carolina. Purni received a B.A. in International Studies at the University of North Carolina at Chapel Hill in 2006 and an M.P.H at the University of South Carolina in 2010. Purni has a wide range of experience in public health research, which includes working in school-based, clinical, and community settings. Purni completed her doctoral studies at the Department of Community Health and Prevention at Drexel University's Dornsife School of Public Health, researching the influence of nutritional intake on weight status among children with cerebral palsy. Purni is passionate about maternal and child health, obesity prevention research, and cooking/eating new foods.